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Population-Based Microcephaly Surveillance in the United States, 2009 to 2013: An Analysis of Potential Sources of Variation

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Background: Congenital microcephaly has been linked to maternal Zika virus infection. However, ascertaining infants diagnosed with microcephaly can be challenging. **Methods:** Thirty birth defects surveillance programs provided data on infants diagnosed with microcephaly born 2009 to 2013. The pooled prevalence of microcephaly per 10,000 live births was estimated overall and by maternal/infant characteristics. Variation in prevalence was examined across case finding methods. Nine programs provided data on head circumference and conditions potentially contributing to microcephaly. **Results:** The pooled prevalence of microcephaly was 8.7 per 10,000 live births. Median prevalence (per 10,000 live births) was similar among programs using active (6.7) and passive (6.6) methods; the interdecile range of prevalence estimates was wider among programs using passive methods for all race/ethnicity categories except Hispanic. Prevalence (per 10,000 live births) was lowest among non-Hispanic Whites (6.5) and highest among non-Hispanic Blacks and Hispanics (11.2 and 11.9, respectively); estimates followed a U-shaped distribution by maternal age with the highest prevalence among mothers <20 years (11.5) and ≥40 years (13.2). For gestational age and birth weight, the highest prevalence was among infants <32 weeks gestation and infants <1500 gm. Case definitions varied; 41.8% of cases had an HC ≥ the 10th percentile for sex and gestational age. **Conclusion:** Differences in methods, population distribution of maternal/infant characteristics, and case definitions for microcephaly can contribute to the wide range of observed prevalence estimates across individual birth defects surveillance programs. Addressing these factors in the setting of Zika virus infection can improve the quality of prevalence estimates.

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Key words: microcephaly; surveillance; prevalence; head circumference

Introduction

Since the first reports of an increased number of infants born with microcephaly in Brazil in September 2015, great strides have been made in characterizing the causal relationship between Zika virus infection during pregnancy and congenital microcephaly, as well as other serious brain abnormalities (Rasmussen et al., 2016; Schuler-Faccini et al., 2016). This work emphasized the value of

Additional Supporting information may be found in the online version of this article.

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comprehensive population-based surveillance data on these defects. The National Birth Defects Prevention Network (NBDPN) was established in 1997 with the mission of improving population-based surveillance of birth defects in the United States (http://www.nbdpn.org). Since 2000, the NBDPN has released annual reports containing state-specific, population-based data on the prevalence of major birth defects; however, ascertaining infants with microcephaly can present challenges for birth defects surveillance programs.

To illustrate, the prevalence of microcephaly for the years 2006 to 2010 estimated by surveillance programs included in the NBDPN Annual Report 2013 ranged from 0.5 to 19.0 per 10,000 live births (Mai et al., 2013). Differences in the clinical definition of microcephaly, the timing and setting of diagnosis, case ascertainment methods, and other factors may have contributed to this wide variation in observed prevalence. For these reasons, microcephaly was dropped from the list of defects requested in the NBDPN Annual Report in 2014 (Mai et al., 2014), but many programs have continued to monitor its prevalence.

The purpose of this report is to describe the estimated prevalence of microcephaly in the United States from 2009 to 2013 using data from thirty population-based birth defects surveillance programs and to explore potential reasons for some of the observed variation in prevalence.

BACKGROUND ON MICROCEPHALY

Microcephaly is the clinical finding of a small head when compared with infants of the same sex and age, or gestational age if measured at birth. The head circumference (HC), also known as the occipitofrontal circumference, is used to assess the volume of the underlying brain (Bray et al., 1969; Cooke et al., 1977). Measurements of HC are compared with standard references and described in terms of percentiles or SDs above or below the mean for the reference population. Clinicians can differ in the reference value they use as the threshold for defining microcephaly or as a trigger for evaluation of an infant for an underlying abnormality. Commonly used thresholds are less than 3rd percentile or more than 2 SD below the mean. Other thresholds used are less than the 5th or 10th percentiles, or more than 3 SDs below the mean (Opitz and Holt, 1990; Raymond and Holmes, 1994; Ashwal et al., 2009). Complicating classification further is that measurement of HC in the newborn or young infant can be inaccurate due to molding of the head following vaginal birth, infant movement, use of tapes that measure only to the nearest half centimeter, and other factors. It is critical to assess head growth, and thus growth of the brain, routinely throughout childhood (Holden, 2014). Microcephaly is confirmed when repeated HC measurements over time remain smaller than expected, or become progressively smaller, compared with infants of the same sex and age.

While the finding of a small HC may suggest an abnormality in the underlying brain, it does not confirm an abnormality or define its nature. Some infants who are constitutionally small overall will have an HC below a given threshold without any underlying brain abnormality. Others may have a small HC due to limitations on growth in utero that are unrelated to brain structure or function. Microcephaly is disproportionate when the HC is small in proportion to infant length and weight, which may be normal for sex and age; or proportionate when the HC, length, and weight are all small for the infant's sex and age, but proportional to each other (Leviton et al., 2002). In congenital microcephaly, the decreased HC is present prenatally or at the time of delivery. However, microcephaly can be acquired postnatally due to a delivery complication or a subsequent insult, such as infection or trauma (Baxter et al., 2009; von der Hagen et al., 2014). In addition, microcephaly that is due to a genetic syndrome may not be present at birth but develop postnatally.

Although most cases of congenital microcephaly have unknown etiology, some causes of congenital microcephaly have been identified (Ashwal et al., 2009). Microcephaly is a known component of some chromosomal abnormalities and single gene disorders (Opitz and Holt, 1990). It is a component of fetal alcohol syndrome and a manifestation of several congenital infections (e.g., cytomegalovirus, toxoplasmosis, and rubella). Congenital microcephaly has been associated with other exposures or conditions including placental insufficiency in utero, poorly controlled maternal diabetes, high levels of radiation exposure, and in utero exposure to the medication hydantoin. The clinical implications, natural history, and developmental potential for infants with microcephaly vary depending on the cause and severity.

Taken together, variations in how microcephaly is defined, the existence of different types, the timing of diagnosis, and the accuracy of gestational age estimates at birth can contribute to variation in the reported prevalence of microcephaly. Microcephaly surveillance is particularly challenging when programs use different methods in terms of the settings where cases are identified (e.g., birth hospitals only, birth and pediatric hospitals, out-patient specialty clinics) and the maximum age at which affected children are ascertained (e.g., newborn only, up to 1 year, up to 3 years). For many programs, limitations on types of data sources and time period for case ascertainment and follow-up are critical. However, the recent increased focus on microcephaly as a consequence of congenital Zika virus infection has led to heightened interest in re-examining the epidemiologic characteristics of microcephaly and improving case ascertainment of this condition.

Materials and Methods

The NBDPN issued a call to state and territorial birth defects surveillance programs for data on infants born from 2009 to 2013 who have a diagnosis of microcephaly (see Supplementary Materials, which are avaiable online).

A total of thirty programs provided data. Typically, cases were identified by the presence of an ICD-9-CM hospital discharge code for microcephaly or mention of microcephaly in the medical record regardless of the HC size. One program was known to have required that the HC measurement be less than the 3rd percentile by sex and gestational age for inclusion in the surveillance. Data provided for each case included the year of birth, maternal race/ethnicity and age at delivery, infant sex, gestational age, birth weight, and plurality. Eight programs also provided information on the specific HC measurement or value of the HC percentile for each case; a ninth provided the number of cases within categories of HC percentiles. These nine programs also included data on the infant's age at the time of the first HC measurement ascertained by the surveillance program, whether the certainty of the microcephaly diagnosis was considered confirmed (definite) or questionable (possible/probable), and the presence of additional conditions that might contribute to microcephaly.

Participating programs were divided into those with active case finding methods and those with passive case finding methods. Generally, in active case finding, children with birth defects are identified through review and abstraction of medical records at data sources, which may include birth and pediatric hospitals, prenatal diagnostic offices, subspecialty offices and other sources; in passive case finding, children with birth defects are identified and reported to the program from administrative datasets at the sources. Some passive programs verify reported diagnoses through subsequent medical record review. Maternal race/ethnicity was categorized as: non-Hispanic White, non-Hispanic Black, Hispanic, non-Hispanic Asian or Pacific Islander, and non-Hispanic American Indian or Alaskan Native, other, and unknown. Infants identified as being of more than one race were bridged to a single race category using data from the National Center for Health Statistics, when available.

When these bridged data were not available, infants of more than one race were assigned to the category of other and unknown race. Maternal age at delivery was categorized as less than 20 years, 20 to 24 years, 25 to 29 years, 30 to 34 years, 35 to 39 years, 40 or more years, and unknown. Gestational age was categorized as term (37 weeks or greater), preterm (32–36 weeks), very preterm (less than 32 weeks), and unknown. Birth weight was categorized as normal (2500 gm or more), low (1500–2499 gm), very low (less than 1500 gm), and unknown. Plurality was categorized as singleton, twin, triplet or higher multiple, and unknown.

The percentile for each newborn HC value from the eight programs that provided these data was calculated using the INTERGROWTH-21st international standards for newborn weight, length, and head circumference by gestational age and sex (available at: https://intergrowth21.tghn.org/articles/international-standards-newborn-weight-length-and-head-circumference-gestational-age-and-sex-newborn-cross-sectional-study-inte/). The INTERGROWTH-21st standards include reference values for term, preterm, and very preterm newborns. The percentile for each HC value taken beyond the birth hospitalization from the programs that provided these data was calculated using the World Health Organization Child Growth Standards (available at: http://www.who.int/childgrowth/standards/hc_for_age/en/). For those cases where HC measurements were not available (less than 1% of cases), the percentile values provided by the state programs were used. Percentiles for HC were categorized as less than 3rd percentile, 3rd to less than 5th percentile, 5th to less than 10th percentile, and greater or equal to 10th percentile. Percentiles for HC were not calculated for infants less than 24 weeks gestation or greater than 42 weeks gestation because reference standards for these infants were not available through INTERGROWTH-21.

Additional conditions that might contribute to microcephaly included other birth defects (neural tube defects, holoprosencephaly, craniosynostosis, and conjoined twins), chromosomal abnormalities and/or clinical syndromes (including fetal alcohol syndrome), and non-Zika in utero infections. All chromosomal abnormalities, clinical syndromes, and in utero infections were included as possibly contributing regardless of whether they were known to be associated with microcephaly. Cases with more than one additional contributing condition were included in each category for which they had a condition.

STATISTICAL ANALYSIS

Data were pooled across thirty programs and the unadjusted prevalence of microcephaly was estimated as the number of reported cases divided by the total live birth population from the corresponding time period overall and by maternal and infant characteristics (Mason et al., 2005). The 95% confidence intervals (CIs) around all prevalence estimates were calculated using the Clopper-Pearson method (Clopper and Pearson, 1934). Prevalence estimates for microcephaly by plurality and gestational age categories (estimates by gestational age category were restricted to singleton infants only) were also stratified by maternal race/ethnicity. To assess variability in the prevalence of microcephaly across programs, the mean, median, interquartile (25th to 75th percentile) and interdecile (10th to 90th percentile) ranges were calculated overall, by case finding methodology (active, passive), and by race/ethnicity. A similar analysis was performed for HC percentiles with the mean, median, interquartile and interdecile ranges calculated by gestational age category.

Results

In Table 1, the counts, unadjusted prevalence estimates, and 95% CIs for microcephaly are presented using pooled data for 2009 to 2013 from all 30 participating birth defects surveillance programs. The total surveillance population covered over 11 million live births during this time period. The pooled unadjusted prevalence for

TABLE 1. *Microcephaly Counts,[a] Prevalence per 10,000 Live Births, and 95% CIs for 30 Birth Defects Surveillance Programs,[b] 2009 to 2013*

	Cases		Live births			
	n	(%)	*n*	(%)	Prev	95% CI
Total cases	9,678	(100.0)	11,110,665	(100.0)	8.7	8.5-8.9
Maternal race/ethnicity						
Non-Hispanic White	3,856	(39.8)	5,973,376	(53.8)	6.5	6.3-6.7
Non-Hispanic Black	1,972	(20.4)	1,758,491	(15.8)	11.2	10.7-11.7
Hispanic	3,071	(31.7)	2,585,605	(23.3)	11.9	11.5-12.3
Non-Hispanic Asian or Pacific Islander	429	(4.4)	566,353	(5.1)	7.6	6.9-8.3
Non-Hispanic American Indian or Alaska Native	54	(<1.0)	51,646	(<1.0)	10.5	7.9-13.6
Maternal age (years)						
<20	1,094	(11.3)	955,420	(8.6)	11.5	10.8-12.1
20-24	2,506	(25.9)	2,608,005	(23.5)	9.6	9.2-10.0
25-29	2,487	(25.7)	3,142,705	(28.3)	7.9	7.6-8.2
30-34	2,010	(20.8)	2,765,901	(24.9)	7.3	7.0-7.6
35-39	1,089	(11.3)	1,312,477	(11.8)	8.3	7.8-8.8
40+	426	(4.4)	322,730	(2.9)	13.2	12.0-14.5
Infant sex						
Male	4,288	(44.3)	5,685,094	(51.2)	7.5	7.3-7.8
Female	5,371	(55.5)	5,425,361	(48.8)	9.9	9.6-10.2
Gestational age						
Term birth (37+ weeks)	6,200	(64.1)	9,960,699	(89.6)	6.2	6.1-6.4
Preterm birth (32 - 36 weeks)	2,271	(23.5)	933,452	(8.4)	24.3	23.3-25.4
Very preterm birth (<32 weeks)	1,088	(11.2)	187,601	(1.7)	58.0	54.6-61.5
Birth weight						
Normal birth weight (2,500+ grams)	5,115	(52.9)	10,169,612	(91.5)	5.0	4.9-5.2
Low birth weight (1,500-2,499 grams)	3,140	(32.4)	760,346	(6.8)	41.3	39.9-42.8
Very low birth weight (<1,500 grams)	1,243	(12.8)	167,771	(1.5)	74.1	70.0-78.3
Plurality						
Singleton	9,130	(94.3)	10,715,456	(96.4)	8.5	8.3-8.7
Twin	455	(4.7)	378,151	(3.4)	12.0	11.0-13.2
Triplet or higher	27	(<1.0)	15,645	(<1.0)	17.3	11.4-25.1

[a]Categories of missing/other/unknown are not shown.

[b]States and territories with surveillance programs contributing to the table: Arkansas, Colorado, Delaware (2009-2012), Florida, Georgia (Metropolitan Atlanta), Hawaii (2012), Illinois, Iowa, Kansas, Kentucky, Louisiana, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New York, North Carolina, North Dakota, Oregon, Puerto Rico (2013), Rhode Island, South Carolina, Texas, Utah, West Virginia, Wisconsin

Prev, prevalence; CI, Confidence Interval.

microcephaly was 8.7 per 10,000 live births (95% CI, 8.5–8.9), or approximately 1 in 1150 births.

MATERNAL AND INFANT CHARACTERISTICS

Prevalence estimates for microcephaly (per 10,000 live births) were lowest among non-Hispanic Whites (6.5) and non-Hispanic Asian or Pacific Islanders (7.6), and highest among non-Hispanic Blacks (11.2) and Hispanics (11.9). Prevalence estimates (per 10,000 live births) by maternal age followed a U-shaped pattern with the highest estimates observed in the youngest (less than 20 years) and oldest (40 years or greater) age categories (11.5 and 13.2, respectively). This U-shaped pattern was generally consistent across all race/ethnicity groups (data not shown).

TABLE 2. *Microcephaly Counts, Prevalence per 10,000 Live Births, and 95% CIs by Maternal Race/Ethnicity, Plurality, and Gestational Age for 30 Birth Defects Surveillance Programs,[a] 2009 to 2013*

Plurality and gestational age	Maternal race/ethnicity																	
	Non-Hispanic White			Non-Hispanic Black			Hispanic			Non-Hispanic Asian or Pacific Islander			Non-Hispanic American Indian or Alaska Native			Total[b]		
	Cases	Prev	95% CI	Cases	Prev	95% CI	Cases	Prev	95% CI	Cases	Prev	95% CI	Cases	Prev	95% CI	Cases	Prev	95% CI
Singleton	3,637	6.3	6.1-6.5	1,863	11.0	10.5-11.5	2,927	11.6	11.2-12.0	399	7.3	6.6-8.0	52	10.4	7.7-13.6	9,130	8.5	8.3-8.7
Term birth (37+ weeks)	2,480	4.7	4.5-4.9	1,117	7.5	7.1-8.0	1,962	8.5	8.1-8.9	290	5.7	5.1-6.4	37	8.1	5.7-11.2	6,062	6.2	6.0-6.3
Preterm birth (32 - 36 weeks)	782	21.7	20.2-23.3	482	31.2	28.5-34.1	683	38.7	35.8-41.7	81	23.8	18.9-29.5	12	30.8	15.9-53.8	2,082	28.1	26.9-29.4
Very preterm birth (< 32 weeks)	352	64.9	58.3-72.1	249	54.7	48.1-61.9	273	87.1	77.1-98.1	25	48.8	31.6-72.1	<5	26.2	3.2-94.8	919	65.8	61.6-70.2
Twin	193	8.6	7.4-9.8	102	15.5	12.6-18.8	124	20.5	17.0-24.4	22	12.3	7.7-18.6	<5	14.1	1.7-50.9	455	12.0	11.0-13.2
Triplet or higher	10	9.5	4.6-17.5	<5	22.5	6.1-57.6	8	38.1	16.4-75.1	5	67.8	22.0-158.1	0	--	--	27	17.3	11.4-25.1

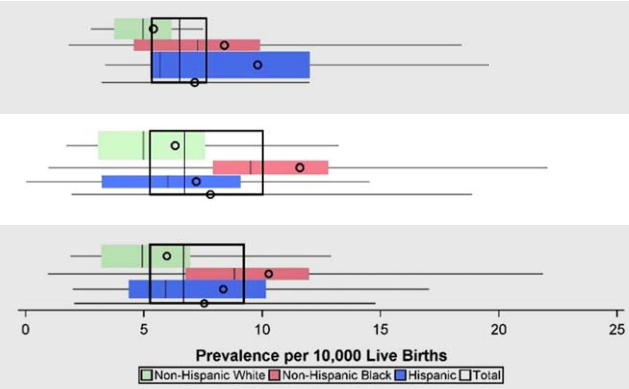
[a]States and territories with surveillance programs contributing to the table: Arkansas, Colorado, Delaware (2009-2012), Florida, Georgia (Metropolitan Atlanta), Hawaii (2012), Illinois, Iowa, Kansas, Kentucky, Louisiana, Massachusetts, Michigan, Minnesota, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New York, North Carolina, North Dakota, Oregon, Puerto Rico (2013), Rhode Island, South Carolina, Texas, Utah, West Virginia, Wisconsin

[b]Missing/other/unknown are included in the total.

Prev, prevalence; CI, Confidence Interval.

TABLE 3. *Microcephaly Prevalence Estimates per 10,000 Live Births: Measures of Central Tendency and Dispersion by Maternal Race/Ethnicity and Case Finding Methodology for 30 Birth Defects Surveillance Programs,[a] 2009 to 2013*

Case finding methodology		Non-Hispanic White	Non-Hispanic Black	Hispanic	Total[b]
Active case finding	Mean (SD)	5.6 (2.8)	8.6 (6.4)	9.9 (8.5)	7.3 (3.9)
	P50 (P10-P90)	5.1 (3.0-7.7)	7.4 (2.0-18.5)	5.9 (3.6-19.7)	6.7 (3.4-12.1)
	(P25-P75)	(3.9-6.3)	(4.8-10.1)	(5.5-12.1)	(5.5-7.8)
Passive case finding	Mean (SD)	6.2 (4.4)	11.5 (10.3)	7.1 (6.3)	7.7 (5.3)
	P50 (P10-P90)	4.9 (1.7-13.1)	9.4 (0.9-21.9)	5.9 (0.0-14.4)	6.6 (1.9-18.7)
	(P25-P75)	(3.0-7.5)	(7.8-12.7)	(3.2-9.0)	(5.2-9.9)
All programs	Mean (SD)	6.0 (3.8)	10.3 (8.9)	8.4 (7.3)	7.5 (4.7)
	P50 (P10-P90)	4.9 (1.9-12.9)	8.8 (0.9-21.9)	5.9 (2.0-17.0)	6.7 (2.0-14.8)
	(P25-P75)	(3.2-6.9)	(6.8-12.0)	(4.3-10.1)	(5.2-9.2)



In the figure, the circle indicates the mean prevalence estimate, the middle vertical bar indicates the median prevalence estimate, the outer vertical bars indicate the interquartile range of prevalence estimates, and the horizontal lines indicate the interdecile range of prevalence estimates.

[a]States and territories with active case finding surveillance programs contributing to the table: Arkansas, Delaware (2009-2012 only), Georgia (Metropolitan Atlanta), Hawaii (2012 only), Iowa, Louisiana, Massachusetts, Minnesota, North Carolina, Puerto Rico (2013 only), South Carolina, Texas, Utah; States with passive case finding surveillance programs contributing to the table: Colorado, Florida, Illinois, Kansas, Kentucky, Michigan, Mississippi, Missouri, Nebraska, Nevada, New Jersey, New York, North Dakota, Oregon, Rhode Island, West Virginia, Wisconsin.

[b]Asian and Pacific Islander, American Indian/Alaska Native, and missing/other/unknown are included in the total.

P10, 10th percentile; P25, 25th percentile; P50, 50th percentile (Median); P75, 75th percentile; P90, 90th percentile; SD, Standard Deviation.

TABLE 4. *Microcephaly Counts[a] for Select Variables, Nine Birth Defects Surveillance Programs,[b] 2009 to 2013*

	Cases	
	n	**(%)**
Total cases	4,766	(100.0)
Time at which earliest HC measurements were taken[c]		
Measured at birth	4,067	(98.4)
Measured beyond the birth hospitalization	51	(1.2)
Unknown	17	(0.4)
HC percentiles[d]		
HC <3rd percentile for age and sex	1,320	(27.8)
HC 3rd to <5th percentile for age and sex	253	(5.3)
HC 5th to <10th percentile for age and sex	494	(10.4)
HC ≥10th percentile for age and sex	1,983	(41.8)
Unknown HC percentile	696	(14.7)
Certainty of diagnosis[e]		
Possible/probable	205	(5.3)
Definite	3,646	(94.7)
Causes[f]		
Documented cause	1,344	(29.5)
Chromosomal abnormality and/or syndrome[g]	1,042	(22.9)
Non-Zika *in utero* infection	100	(2.2)
Other birth defect potentially associated with microcephaly[h]	304	(6.7)
No documented cause	3,206	(70.5)

[a]The total counts for each variable differ because some programs were unable to provide all of the variables.

[b]States and territories with surveillance programs contributing to the table: Georgia (Metropolitan Atlanta), Massachusetts, Michigan, Minnesota, North Carolina, Puerto Rico (2013 only), Rhode Island, Texas, Utah.

[c]Includes only cases with an HC measurement available from 9 birth defects surveillance programs (n = 4,135).

[d]Includes data for eight birth defects surveillance programs (n = 4,746); one program was excluded because their case definition required an HC less than 3rd percentile.

[e]Includes data for six birth defects surveillance programs (n = 3,851).

[f]Includes data for seven birth defects surveillance programs (n = 4,550). Cases with more than one potential cause are included in each category for which they had a condition.

[g]Includes fetal alcohol syndrome.

[h]Includes neural tube defects, holoprosencephaly, craniosynostosis, and conjoined twins.

HC, Head Circumference.

The estimated prevalence of microcephaly increased with decreasing gestational age and with decreasing birth weight. For gestational age, the estimated prevalence (per 10,000 live births) was highest among very preterm births at less than 32 weeks gestation (58.0) and lowest among term births at 37 weeks or more gestation (6.2). For birth weight, the estimated prevalence (per 10,000 live births) was highest among infants with very low birth weight of less than 1500 gm (74.1) and lowest among infants with normal birth weight of 2500 gm or greater (5.0). The estimated prevalence of microcephaly (per 10,000 live births) also was higher among twins (12.0) and triplets or higher multiples (17.3) compared with that for singletons (8.5).

Because race/ethnicity can be associated with the distribution of preterm and multiple births in a population, microcephaly prevalence estimates for these characteristics were stratified by maternal race/ethnicity (Table 2). Prevalence estimates of microcephaly increased with decreasing gestational age among singleton births within every maternal race/ethnicity category, although the CIs were particularly wide for non-Hispanic American Indians and Alaska Natives due to the small number of affected infants. Similarly, prevalence estimates for twins and triplets or higher multiples were generally greater compared with singletons across maternal racial/ethnic categories.

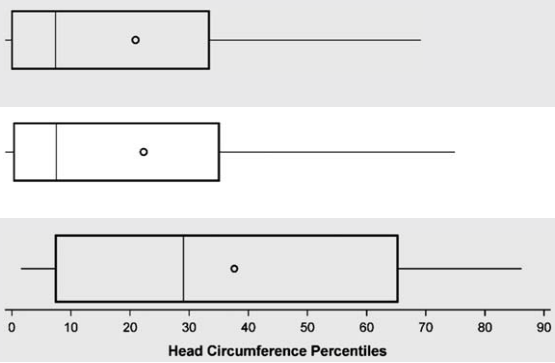
CASE FINDING METHODOLOGY

In Table 3, the mean with standard deviation, median (P50), interquartile interval range (P25–P75) and interdecile range (P10–P90) for the prevalence estimates of microcephaly are presented for birth defects surveillance programs by type of case finding methodology (active, passive) stratified by maternal race/ethnicity. In this analysis, each program carried an equal weight regardless of population size. The accompanying figure displays the mean (circle), median (middle vertical bar), interquartile range (outer vertical bars), and interdecile interval (horizontal lines). The vertical width of each box represents the percent of total cases contributed by each race/ethnicity group. Non-Hispanic Whites are shown in green, non-Hispanic Blacks in pink, Hispanics in blue, and total for all race/ethnicities in white. Race/ethnicity categories that provided less than 10% of the total cases are not shown. A visual explanation of a similar figure was presented in the 2015 NBDPN Annual Report (Mai et al., 2015).

Among programs with active case finding, the mean estimated prevalence of microcephaly (per 10,000 live births) was 7.3 and the median was 6.7, with 80% of programs reporting a prevalence between 3.4 and 12.1 (Table 3). Among programs with passive case finding, the mean estimated prevalence of microcephaly (per 10,000 live births) was 7.7 and the median was 6.6, with 80% of programs reporting a prevalence between 1.9 and 18.7. The variability in prevalence estimates, as indicated by the width of the interdecile range, was greater for birth defects surveillance programs with passive compared with active case finding for all race/ethnicity categories except Hispanic ethnicity. Programs that used active case finding

TABLE 5. *Microcephaly HC Percentiles:[a] Measures of Central Tendency and Dispersion by Gestational Age for Seven Birth Defects Surveillance Programs,[b] 2009 to 2013*

Gestational age		HC percentiles
Term birth (37+ weeks)	Mean (SD)	22.2 (28.0)
	P50 (P10-P90)	8.7 (0.2-70.2)
	(P25-P75)	(1.4-34.5)
Preterm birth	Mean (SD)	23.4 (29.3)
(32 - 36 weeks)	P50 (P10-P90)	8.7 (0.1-75.9)
	(P25-P75)	(1.6-36.1)
Very preterm birth	Mean (SD)	37.6 (31.9)
(< 32 weeks)	P50 (P10-P90)	29.0 (1.5-86.2)
	(P25-P75)	(7.4-65.2)



In the figure, the circle indicates the mean HC percentile, the middle vertical bar indicates the median HC percentile, the outer vertical bars indicate the interquartile range of HC percentiles, and the horizontal lines indicate the interdecile range of HC percentiles.

[a]Limited to microcephaly cases with head circumference measurements taken at birth; includes twins and higher multiples.

[b]States with surveillance programs contributing to the table: Georgia (Metropolitan Atlanta), Michigan, Minnesota, North Carolina, Rhode Island, Texas, Utah.

P10, 10th percentile; P25, 25th percentile; P50, 50th percentile (Median); P75, 75th percentile; P90, 90th percentile; SD, Standard Deviation; HC, Head Circumference.

methods reported the highest mean prevalence (per 10,000 live births) among Hispanics (9.9). Hispanics also accounted for the largest proportion of total cases among programs with active case finding. The next highest mean prevalence (per 10,000 live births) among programs with active case finding was for non-Hispanic Blacks (8.6) followed by non-Hispanic Whites (5.6).

Programs that used passive case finding methods reported the highest mean prevalence (per 10,000 live births) among non-Hispanic Blacks (11.5), followed by Hispanics (7.1) and non-Hispanic Whites (6.2). Non-Hispanic Whites accounted for the largest proportion of total cases among these programs. The median estimated prevalence of microcephaly among programs with active and those with passive case finding were similar for all race/ethnicity categories except non-Hispanic Black. Non-Hispanic Black was also the race/ethnicity category that contributed the lowest proportion of cases regardless of case finding methodology. For both types of programs, the median prevalence estimates were lower than the mean estimates, presumably because the median value is less influenced by outliers and less subject to skewing by data from programs with very high prevalence estimates.

ADDITIONAL DATA ON MICROCEPHALY DIAGNOSES

Additional data on microcephaly diagnoses provided by nine birth defects surveillance programs are presented in Table 4. Six of the nine programs provided information on the certainty of the microcephaly diagnosis. Almost 95% of the cases reported by these six programs were considered to have a definite microcephaly diagnosis; 5.3% (205/3851) were considered to have a possible/probable diagnosis. Seven programs were able to provide data on additional conditions that might contribute to microcephaly. Almost 30% of cases from these programs had at least one additional contributing condition; 22.9% had a chromosomal abnormality or syndrome, 2.2% had documentation of a non-Zika in utero infection, and 6.7% had other birth defects (neural tube defects, holoprosencephaly, craniosynostosis, or conjoined twins).

One of the nine programs was dropped from the analysis of HC percentiles because their case definition required that cases have an HC less than the 3rd percentile for gestational age and sex to be included in the surveillance. Among the remaining eight programs, 27.8% of cases had a HC measurement less than 3rd percentile; 41.8% had a HC measurement greater than or equal to the 10th percentile. Head circumference percentiles could not be calculated for 14.7% of cases from these eight programs due to missing HC measurements, sex, or gestational age values, or because the infants were less than 24 weeks or greater than 42 weeks gestation at birth. Slightly more than 98% of the HC measurements provided were taken during the birth hospitalization.

Analysis of the variability of HC percentiles by gestational age category is presented for seven programs in Table 5. The figure accompanying Table 5 displays the mean (circle), median (middle vertical bar), interquartile range (outer vertical bars), and interdecile range (horizontal lines) for HC percentiles. The one program that provided only the number of cases within each HC percentile

category was dropped from this analysis. In general, the mean HC percentile increased with decreasing gestational age (22.2 among term births, 23.4 among preterm births and 37.6 among very pretem births). The median HC percentile was the same for term and preterm births (8.7) but much higher for very preterm births (29.0). While the interdecile ranges were similar for all three groups, the interquartile range for very preterm births was much wider (7.4–65.2) than for term or preterm births (1.4–34.5 and 1.6–36.1, respectively).

Discussion

The pooled estimated prevalence of microcephaly from 2009 to 2013 among 30 population-based birth defects surveillance programs in the United States was 8.7 per 10,000 live births (95% CI, 8.5–8.9). Worldwide, the reported prevalence of microcephaly varies widely. The European Surveillance of Congenital Anomalies (EUROCAT) reported an overall prevalence of microcephaly of 2.85 per 10,000 live births (95% CI, 2.69–3.02) among full member registries for birth years 2008 to 2012 (http://www.eurocat-network.eu/ACCESSPREVALENCEDATA/PrevalenceTables). Among population-based programs included in the 2014 annual report of the International Clearinghouse for Birth Defects, the prevalence estimates for microcephaly for the most recent available birth year (2011, 2012, or 2013) varied widely from 0.42 to 21.24 per 10,000 live births (http://www.icbdsr.org/filebank/documents/ar2005/Report2014.pdf).

The data in this report demonstrate several factors that could contribute to the observed variation in the prevalence of microcephaly across U.S. birth defects surveillance programs. While there was little difference in the median prevalence estimates of microcephaly among programs with active versus passive surveillance methods, the estimates among programs with active case finding generally showed less variability. This may be due to a combination of more rigorous case finding and confirmation of suspected cases. A higher estimated prevalence of defects other than microcephaly by programs with active compared with passive case finding has been demonstrated, presumably reflecting more complete case ascertainment (Parker et al., 2010; Mai et al., 2015).

In this issue of the journal, investigators with the Utah Birth Defect Network (UBDN) evaluated their ascertainment of microcephaly (Steele et al., 2016). Their results demonstrated the variability of ascertainment depending on the source and method of case finding. The UBDN uses a combination of active and passive case finding methods. They found that 53% of all potential cases of microcephaly reported to the UBDN were subsequently confirmed as true cases. The sources of case ascertainment with the highest positive predictive value for confirmed microcephaly included tertiary neonatal intensive care units and pediatric specialty clinics including genetics and ophthalmology. Approximately 50% of reports from vital records and hospital discharge data were subsequently confirmed to have microcephaly. Cases reported by multiple sources were more likely to be true cases of microcephaly.

The distribution of HC percentiles among birth defects surveillance programs that were able to submit these data demonstrates wide variation in the clinical definition of microcephaly. Almost 42% of the cases had an HC greater than or equal to the 10^{th} percentile for age and sex. Such differences in the definition of microcephaly may account for much of the variation in prevalence estimates across surveillance programs, and is one reason that surveillance for microcephaly is considered particularly problematic. Identification of children with mention of microcephaly in the medical record, the approach taken by many birth defects surveillance programs, will include children with a wide range of HC percentiles. In contrast, identification of all children with an HC below a certain percentile value would inevitably include some children who are constitutionally small but otherwise clinically normal, and currently is not logistically practical on a population basis.

The data in this report show a striking increase in the prevalence of microcephaly with decreasing gestational age and birth weight. Reference data for growth parameters at birth for very preterm infants tend to be based on smaller samples than for term infants, which may affect the precision of the reference values. The small size of these infants overall also might lead to increased mention of small head size in the medical record relative to that for larger preterm or term infants. Regardless of the accuracy of the measurement or diagnosis, variations in the proportion of preterm infants and low birth weight infants in populations could contribute to differences in the resulting estimates of the prevalence of microcephaly.

The estimated prevalence of microcephaly in these data also varied by maternal race/ethnicity, maternal age, and plurality. Children of Hispanic and non-Hispanic Black mothers had a substantially higher estimated prevalence of microcephaly compared with children of non-Hispanic White mothers and a moderately higher prevalence compared with children of non-Hispanic Asian or Pacific Island mothers. The increased variability among prevalence estimates for Hispanics from programs using active case finding methods may partly be driven by the high proportion of this ethnic group in the active program that contributed the largest number of microcephaly cases. The fact that the median prevalence estimate among non-Hispanic Blacks was the highest regardless of ascertainment method supports the finding of a true higher prevalence of microcephaly in non-Hispanic Blacks.

As a result, the racial/ethnic distribution of mothers giving birth in different populations could contribute to

differences in observed prevalence estimates for microcephaly. A U-shaped distribution of microcephaly prevalence by maternal age was apparent for all racial/ethnic groups examined, indicating that the age distribution of mothers in different populations also could contribute to differences in observed prevalence estimates. Similarly, the proportion of mothers giving birth to twin or higher multiple infants in different populations also could affect the estimated prevalence of microcephaly. While these deliveries generally constitute a small proportion of most populations, the increasing use of artificial reproductive technology and resultant increase in multiple births may vary across populations.

CONCLUSIONS

The recent spread of Zika virus highlights the critical role that birth defects surveillance programs can play in response to an emerging epidemic or other public health threat affecting mothers and infants. This includes characterizing the public health impact of an exposure and monitoring the effects of prevention efforts. High quality population-based birth defects surveillance data can support a timely response to these threats. However, few birth defects surveillance programs in the United States currently have the infrastructure, resources, and personnel in place to conduct "rapid" surveillance for birth defects while simultaneously ensuring accuracy and completeness. Timeliness of reporting, case ascertainment, and data collection are all areas of potential improvement. The NBDPN continues to develop standards and tools to support programs to achieve this goal. In the absence of a nationwide population-based registry for birth defects, the data collected from state and territorial birth defects surveillance programs through the NBDPN provides the largest source of data regarding the prevalence of birth defects, including microcephaly, in the United States

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Major birth Defects from Population-based birth defects surveillance programs in the United States, 2009-2013

The current report includes state-specific data on the 47 major birth defects from 40 population-based birth defects surveillance programs, as well as an accompanying directory. The directory describes data collection status and contacts for state birth defects surveillance programs. **Table 1** presents the NBDPN list of birth defects and their accompanying ICD-9-CM and CDC/BPA diagnostic codes.

Methodology

In collaboration with the CDC, the NBDPN Data Committee issued a call for data in April 2016 for the 47 major birth defects. State programs were provided with a data dictionary and data table creation tools in Excel and SAS for the reporting of major birth defects. All data were received by CDC for data quality checks and formatting. Tables were generated and provided to state programs to allow them to validate their data and approve the final data presentation.

Participating birth defects surveillance programs submitted case counts of the reportable birth defects and live births occurring from January 1, 2009 through December 31, 2013. These cases were stratified by U.S. Census maternal racial/ethnic groups: non-Hispanic white, non-Hispanic black, Hispanic, non-Hispanic Asian/Pacific Islander, non-Hispanic American Indian/Alaska Native, and other/unknown. Additionally, trisomy conditions (trisomy 21 [Down syndrome], trisomy 13, and trisomy 18) and gastroschisis were stratified by six maternal age categories: less than 20 years, 20 to 24 years, 25 to 29 years, 30 to 34 years, 35 to 39 years, and 40+ years.

Data presentation

State-specific data from 40 population-based birth defects surveillance programs for 2009 to 2013 are included in the supplemental materials. The data are presented in two tables for each state. The first table shows defect counts and prevalence per 10,000 live births by maternal racial/ethnic categories, and the second table presents counts and prevalence for trisomies and gastroschisis by two maternal age categories (less than 35 years, 35+ years). The prevalence is calculated by dividing the number of birth defect cases for any pregnancy outcome by the total number of live births for the reported years and then multiplying by 10,000 (Mason et al. 2005). The denominator used to calculate the prevalence for all birth defects is total live births except for hypospadias, which is calculated using total male live births, and Turner syndrome, which is calculated using total female live births. The NBDPN provided a data

dictionary and attempted to obtain the data in a uniform manner; however, some variability can be expected in the reported birth defects data by state programs, given differences in coding systems used for case inclusion, case-finding methodology, and available data sources. State-specific notes and clarification about the data, including methodological changes and probable/possible diagnoses, are noted in the data tables. Additional information about each state program data collection methodology is available in the accompanying program directory.

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Table 1: National Birth Defects Prevention Network (NBDPN) List of Reported Birth Defects by Disease Classification Codes

Birth Defects	Disease Classification Codes	
	International Classification of Diseases, 9th Revision, Clinical Modification **(ICD-9-CM)**	Centers for Disease Control and Prevention/British Pediatric Association Classification of Diseases (**CDC/BPA**)
Central Nervous System		
Anencephaly	740.0 – 740.1	740.00 – 740.10
Spina bifida without anencephaly	741.0, 741.9 without 740.0 - 740.1	741.00 – 741.99 without 740.00 – 740.10
Encephalocele	742.0	742.00 – 742.09
Holoprosencephaly	742.2	742.26
Eye		
Anophthalmia/microphthalmia	743.0, 743.1	743.00 – 743.10
Congenital cataract	743.30 – 743.34	743.32
Ear		
Anotia/microtia	744.01, 744.23	744.01, 744.21
Cardiovascular		
Common truncus (truncus arteriosus)	745.0	745.00 (excluding 745.01)
Transposition of the great arteries (TGA)	745.10, .12, .19	745.10 – 745.12, 745.18 – 745.19
dextro-Transposition of great arteries (d-TGA) – for CCHD screening*	745.10	745.10, 745.11,745.19
Tetralogy of Fallot	745.2	745.20 – 745.21, 747.31
Ventricular septal defect	745.4	745.40 – 745.49 (excluding 745.487, 745.498)
Atrial septal defect	745.5	745.51 – 745.59
Atrioventricular septal defect (endocardial cushion defect)	745.60, .61, .69	745.60 – 745.69, 745.487
Pulmonary valve atresia and stenosis	746.01, 746.02	746.00, 746.01
Pulmonary valve atresia – for CCHD screening*	746.01	746.00
Tricuspid valve atresia and stenosis	746.1	746.100, 746.106 (excluding 746.105)
Tricuspid valve atresia– for CCHD screening*	746.1	746.100
Ebstein anomaly	746.2	746.20
Aortic valve stenosis	746.3	746.30
Hypoplastic left heart syndrome	746.7	746.70
Coarctation of aorta	747.10	747.10 – 747.19
Total anomalous pulmonary venous connection	747.41	747.42
Single ventricle	745.3	745.3
Interrupted aortic arch	747.11	747.215 – 747.217
Double outlet right ventricle	745.11	745.13 – 745.15
Orofacial		
Cleft palate alone (without cleft lip)	749.0	749.00 – 749.09
Cleft lip alone (without cleft palate)	749.1	749.10 – 749.19
Cleft lip with cleft palate	749.20-749.25	749.20 – 749.29
Choanal atresia	748.0	748.00

Birth Defects	Disease Classification Codes	
	International Classification of Diseases, 9th Revision, Clinical Modification **(ICD-9-CM)**	Centers for Disease Control and Prevention/British Pediatric Association Classification of Diseases (**CDC/BPA**)
Gastrointestinal		
Esophageal atresia/tracheoesophageal fistula	750.3	750.30 – 750.35
Rectal and large intestinal atresia/stenosis	751.2	751.20 – 751.24
Biliary atresia	751.61	751.65
Small intestinal atresia/stenosis	751.1	751.10 – 751.19
Genitourinary		
Renal agenesis/hypoplasia	753.0	753.00 – 753.01
Bladder exstrophy	753.5	753.50
Hypospadias	752.61	752.60 – 752.62 (excluding 752.61 and 752.621)
Congenital posterior urethral valves	753.6	753.60
Cloacal exstrophy	751.5	751.555
Musculoskeletal		
Gastroschisis	756.73 (as of 10/1/09)	756.71
Omphalocele	756.72 (as of 10/1/09)	756.70
Diaphragmatic hernia	756.6	756.610 – 756.617
Limb deficiencies (reduction defects)	755.2 – 755.4	755.20 – 755.49
Craniosynostosis	No specific code	756.00 – 756.03
Clubfoot	754.51, 754.70	754.50, 754.73 (excluding 754.735)
Chromosomal		
Trisomy 13	758.1	758.10 – 758.19
Trisomy 21 (Down syndrome)	758.0	758.00 – 758.09
Trisomy 18	758.2	758.20 – 758.29
Turner syndrome	758.6	758.60 – 758.69
Deletion 22q11.2	758.32	758.37

CCHD: critical congenital heart defect.

***** The primary targets for CCHD screening include 7 conditions: hypoplastic left heart syndrome, pulmonary atresia with intact septum, tetralogy of Fallot, total anomalous pulmonary venous connection, dextro-transposition of great arteries (d-TGA), tricuspid atresia, and truncus arteriosus. The NBDPN traditionally monitors all TGA, and both atresia and stenosis for pulmonary and tricuspid valve conditions; however, for CCHD screening reporting purpose, these conditions are also reported as d-TGA, pulmonary valve atresia, and tricuspid valve atresia.

Arizona

Birth Defects Counts and Prevalence 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	10	2	33	0	2	47	
	0.6	***1.2***	***2.4***	***0.0***	***0.9***	***1.3***	
Anophthalmia/microphthalmia	16	1	16	2	3	38	
	1.0	***0.6***	***1.1***	***1.5***	***1.3***	***1.1***	
Anotia/microtia	12	1	17	1	5	36	
	0.8	***0.6***	***1.2***	***0.8***	***2.2***	***1.0***	
Aortic valve stenosis	26	3	30	1	6	66	
	1.7	***1.8***	***2.1***	***0.8***	***2.7***	***1.9***	
Atrioventricular septal defect (Endocardial cushion defect)	21	6	23	1	4	55	1
	2.7	***7.2***	***3.5***	***1.5***	***3.6***	***3.2***	
Biliary atresia	4	1	5	2	2	15	
	0.3	***0.6***	***0.4***	***1.5***	***0.9***	***0.4***	
Bladder exstrophy	4	0	1	0	0	5	
	0.3	***0.0***	***0.1***	***0.0***	***0.0***	***0.1***	
Choanal atresia	14	3	13	1	0	33	
	0.9	***1.8***	***0.9***	***0.8***	***0.0***	***0.9***	
Cleft lip alone	60	1	41	4	18	124	
	3.9	***0.6***	***2.9***	***3.1***	***8.0***	***3.5***	
Cleft lip with cleft palate	88	7	105	6	24	236	
	5.7	***4.3***	***7.5***	***4.6***	***10.7***	***6.7***	
Cleft palate alone	91	4	77	12	19	203	
	5.9	***2.4***	***5.5***	***9.3***	***8.5***	***5.8***	
Coarctation of the aorta	64	9	64	2	12	151	
	4.1	***5.5***	***4.6***	***1.5***	***5.3***	***4.3***	
Common truncus (truncus arteriosus)	5	0	5	0	2	12	
	0.3	***0.0***	***0.4***	***0.0***	***0.9***	***0.3***	
Congenital cataract	7	2	10	1	1	22	
	0.5	***1.2***	***0.7***	***0.8***	***0.4***	***0.6***	
Diaphragmatic hernia	32	2	37	1	5	80	
	2.1	***1.2***	***2.6***	***0.8***	***2.2***	***2.3***	
Ebstein anomaly	11	0	14	1	4	31	
	0.7	***0.0***	***1.0***	***0.8***	***1.8***	***0.9***	
Encephalocele	10	0	12	1	2	25	
	0.6	***0.0***	***0.9***	***0.8***	***0.9***	***0.7***	
Esophageal atresia/tracheoesophageal fistula	40	4	29	2	6	82	
	2.6	***2.4***	***2.1***	***1.5***	***2.7***	***2.3***	
Gastroschisis	76	13	106	3	22	227	
	4.9	***7.9***	***7.6***	***2.3***	***9.8***	***6.5***	
Holoprosencephaly	3	0	6	0	0	9	2
	0.8	***0.0***	***1.8***	***0.0***	***0.0***	***1.1***	
Hypoplastic left heart syndrome	40	8	36	3	9	96	
	2.6	***4.9***	***2.6***	***2.3***	***4.0***	***2.7***	
Interrupted aortic arch	1	0	2	0	0	3	2
	0.3	***0.0***	***0.6***	***0.0***	***0.0***	***0.4***	
Limb deficiencies (reduction defects)	41	10	38	1	9	100	
	2.7	***6.1***	***2.7***	***0.8***	***4.0***	***2.9***	
Omphalocele	38	2	22	4	2	68	
	2.5	***1.2***	***1.6***	***3.1***	***0.9***	***1.9***	
Pulmonary valve atresia and stenosis	85	11	84	5	17	206	
	5.5	***6.7***	***6.0***	***3.9***	***7.6***	***5.9***	
Pulmonary valve atresia	39	6	39	3	6	96	
	2.5	***3.7***	***2.8***	***2.3***	***2.7***	***2.7***	
Single ventricle	12	1	15	0	1	29	
	0.8	***0.6***	***1.1***	***0.0***	***0.4***	***0.8***	
Spina bifida without anencephalus	53	5	49	4	13	129	
	3.4	***3.1***	***3.5***	***3.1***	***5.8***	***3.7***	
Tetralogy of Fallot	64	5	62	5	14	154	
	4.1	***3.1***	***4.4***	***3.9***	***6.2***	***4.4***	
Total anomalous pulmonary venous connection	13	2	17	1	4	38	3
	1.1	***1.6***	***1.7***	***1.0***	***2.4***	***1.5***	

Arizona

Birth Defects Counts and Prevalence 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Transposition of the great arteries (TGA)	54	8	64	3	10	139	
	3.5	***4.9***	***4.6***	***2.3***	***4.5***	***4.0***	
Dextro-transposition of great arteries (d-TGA)	33	1	38	2	3	77	
	2.1	***0.6***	***2.7***	***1.5***	***1.3***	***2.2***	
Tricuspid valve atresia and stenosis	6	1	9	2	1	19	3
	0.5	***0.8***	***0.9***	***2.0***	***0.6***	***0.7***	
Trisomy 13	12	4	16	3	1	36	
	0.8	***2.4***	***1.1***	***2.3***	***0.4***	***1.0***	
Trisomy 18	32	4	21	3	4	64	
	2.1	***2.4***	***1.5***	***2.3***	***1.8***	***1.8***	
Trisomy 21 (Down syndrome)	177	17	205	14	30	449	
	11.5	***10.4***	***14.6***	***10.8***	***13.4***	***12.8***	
Total live births	**154265**	**16382**	**139948**	**12941**	**22437**	**350113**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

Arizona

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	219	8	227	
	7.2	***1.7***	***6.5***	
Trisomy 13	25	11	36	
	0.8	***2.3***	***1.0***	
Trisomy 18	37	26	64	
	1.2	***5.5***	***1.8***	
Trisomy 21 (Down syndrome)	239	210	449	
	7.9	***44.2***	***12.8***	
Total live births	**302599**	**47514**	**350113**	

**Total includes unknown maternal age

Notes
1.Data for this condition begin mid-year 2011.
2.Data for this condition begin in 2012.
3.Data for this condition begin in 2010.

General comments
-Data does not include terminations.
-Stillborn cases are included in this report if there is a fetal death certificate, regardless of fetal weight or gestational age.

Arkansas

Birth Defects Counts and Prevalence 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	39	6	6	1	1	53	
	3.8	***2.0***	***3.8***	***3.4***	***12.6***	***3.4***	
Anophthalmia/microphthalmia	24	5	3	1	0	33	
	2.3	***1.7***	***1.9***	***3.4***	***0.0***	***2.1***	
Anotia/microtia	19	1	14	0	0	34	
	1.8	***0.3***	***8.8***	***0.0***	***0.0***	***2.2***	
Aortic valve stenosis	51	3	9	0	0	66	
	4.9	***1.0***	***5.6***	***0.0***	***0.0***	***4.3***	
Atrial septal defect	360	103	61	17	1	596	
	34.7	***35.1***	***38.1***	***58.3***	***12.6***	***38.8***	
Atrioventricular septal defect (Endocardial cushion defect)	81	24	9	4	0	120	
	7.8	***8.2***	***5.6***	***13.7***	***0.0***	***7.8***	
Biliary atresia	5	0	2	1	0	11	
	0.5	***0.0***	***1.3***	***3.4***	***0.0***	***0.7***	
Bladder exstrophy	3	1	1	0	0	5	
	0.3	***0.3***	***0.6***	***0.0***	***0.0***	***0.3***	
Choanal atresia	4	2	0	0	0	6	
	0.4	***0.7***	***0.0***	***0.0***	***0.0***	***0.4***	
Cleft lip alone	45	5	4	0	1	56	
	4.3	***1.7***	***2.5***	***0.0***	***12.6***	***3.6***	
Cleft lip with cleft palate	85	12	12	2	0	115	
	8.2	***4.1***	***7.5***	***6.9***	***0.0***	***7.5***	
Cleft palate alone	82	11	9	1	0	108	
	7.9	***3.8***	***5.6***	***3.4***	***0.0***	***7.0***	
Cloacal exstrophy	1	2	0	0	0	3	
	0.1	***0.7***	***0.0***	***0.0***	***0.0***	***0.2***	
Clubfoot	215	35	31	2	1	290	
	20.7	***11.9***	***19.4***	***6.9***	***12.6***	***18.9***	
Coarctation of the aorta	94	11	9	0	0	120	
	9.1	***3.8***	***5.6***	***0.0***	***0.0***	***7.8***	
Common truncus (truncus arteriosus)	10	1	2	1	0	14	
	1.0	***0.3***	***1.3***	***3.4***	***0.0***	***0.9***	
Congenital cataract	37	8	4	3	0	57	
	3.6	***2.7***	***2.5***	***10.3***	***0.0***	***3.7***	
Congenital posterior urethral valves	17	9	2	0	0	30	
	1.6	***3.1***	***1.3***	***0.0***	***0.0***	***2.0***	
Craniosynostosis	71	6	10	0	0	100	
	6.8	***2.0***	***6.3***	***0.0***	***0.0***	***6.5***	
Deletion 22q11.2	8	1	2	0	0	13	
	0.8	***0.3***	***1.3***	***0.0***	***0.0***	***0.8***	
Diaphragmatic hernia	40	10	6	0	1	60	
	3.9	***3.4***	***3.8***	***0.0***	***12.6***	***3.9***	
Double outlet right ventricle	22	12	3	1	0	38	
	2.1	***4.1***	***1.9***	***3.4***	***0.0***	***2.5***	
Ebstein anomaly	8	0	5	0	0	15	
	0.8	***0.0***	***3.1***	***0.0***	***0.0***	***1.0***	
Encephalocele	10	9	1	1	0	23	
	1.0	***3.1***	***0.6***	***3.4***	***0.0***	***1.5***	
Esophageal atresia/tracheoesophageal fistula	33	7	2	0	0	44	
	3.2	***2.4***	***1.3***	***0.0***	***0.0***	***2.9***	
Gastroschisis	93	14	13	2	1	123	
	9.0	***4.8***	***8.1***	***6.9***	***12.6***	***8.0***	
Holoprosencephaly	24	5	1	1	1	34	
	2.3	***1.7***	***0.6***	***3.4***	***12.6***	***2.2***	
Hypoplastic left heart syndrome	31	7	1	0	0	41	
	3.0	***2.4***	***0.6***	***0.0***	***0.0***	***2.7***	
Hypospadias*	533	115	21	10	1	728	
	99.9	***77.2***	***25.7***	***67.9***	***23.9***	***92.3***	
Interrupted aortic arch	6	3	1	1	0	12	
	0.6	***1.0***	***0.6***	***3.4***	***0.0***	***0.8***	

Arkansas

Birth Defects Counts and Prevalence 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	64	24	10	1	2	104	
	6.2	***8.2***	***6.3***	***3.4***	***25.3***	***6.8***	
Omphalocele	27	12	4	0	0	43	
	2.6	***4.1***	***2.5***	***0.0***	***0.0***	***2.8***	
Pulmonary valve atresia and stenosis	152	48	24	8	1	251	
	14.7	***16.4***	***15.0***	***27.4***	***12.6***	***16.3***	
Pulmonary valve atresia	7	4	3	0	0	15	
	0.7	***1.4***	***1.9***	***0.0***	***0.0***	***1.0***	
Rectal and large intestinal atresia/stenosis	39	9	5	2	0	60	
	3.8	***3.1***	***3.1***	***6.9***	***0.0***	***3.9***	
Renal agenesis/hypoplasia	25	5	8	0	0	39	
	2.4	***1.7***	***5.0***	***0.0***	***0.0***	***2.5***	
Single ventricle	4	3	2	0	0	9	
	0.4	***1.0***	***1.3***	***0.0***	***0.0***	***0.6***	
Small intestinal atresia/stenosis	29	8	8	1	0	53	
	2.8	***2.7***	***5.0***	***3.4***	***0.0***	***3.4***	
Spina bifida without anencephalus	44	8	12	2	0	66	
	4.2	***2.7***	***7.5***	***6.9***	***0.0***	***4.3***	
Tetralogy of Fallot	47	11	7	1	1	72	
	4.5	***3.8***	***4.4***	***3.4***	***12.6***	***4.7***	
Total anomalous pulmonary venous connection	10	4	2	1	0	21	
	1.0	***1.4***	***1.3***	***3.4***	***0.0***	***1.4***	
Transposition of the great arteries (TGA)	49	10	4	4	0	70	
	4.7	***3.4***	***2.5***	***13.7***	***0.0***	***4.6***	
Dextro-transposition of great arteries (d-TGA)	28	4	3	3	0	40	
	2.7	***1.4***	***1.9***	***10.3***	***0.0***	***2.6***	
Tricuspid valve atresia and stenosis	6	3	2	1	0	12	
	0.6	***1.0***	***1.3***	***3.4***	***0.0***	***0.8***	
Tricuspid valve atresia	6	3	2	1	0	12	
	0.6	***1.0***	***1.3***	***3.4***	***0.0***	***0.8***	
Trisomy 13	11	5	2	0	0	18	
	1.1	***1.7***	***1.3***	***0.0***	***0.0***	***1.2***	
Trisomy 18	30	7	8	1	0	47	
	2.9	***2.4***	***5.0***	***3.4***	***0.0***	***3.1***	
Trisomy 21 (Down syndrome)	129	28	23	3	0	190	
	12.4	***9.6***	***14.4***	***10.3***	***0.0***	***12.4***	
Turner syndrome†	16	0	3	0	0	19	
	3.2	***0.0***	***3.8***	***0.0***	***0.0***	***2.5***	
Ventricular septal defect	650	123	126	25	2	999	
	62.7	***42.0***	***78.8***	***85.8***	***25.3***	***65.0***	
Total live births §	**103721**	**29313**	**15996**	**2915**	**792**	**153792**	
Male live births	**53376**	**14890**	**8187**	**1472**	**418**	**78855**	
Female live births	**50342**	**14421**	**7808**	**1443**	**374**	**74931**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Arkansas

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	121	2	123	
	8.6	***1.6***	***8.0***	
Trisomy 13	14	4	18	
	1.0	***3.2***	***1.2***	
Trisomy 18	29	18	47	
	2.1	***14.4***	***3.1***	
Trisomy 21 (Down syndrome)	105	81	190	
	7.4	***64.7***	***12.4***	
Total live births	**141265**	**12513**	**153792**	

**Total includes unknown maternal age

General comments
-Data for 2013 are provisional.

California

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	<5	0	46	<5	0	94	
	.	***0.0***	***2.3***	.	***0.0***	***2.9***	
Anophthalmia/microphthalmia	8	<5	19	<5	0	36	
	1.0	.	***1.0***	.	***0.0***	***1.1***	
Anotia/microtia	9	<5	90	<5	0	111	
	1.1	.	***4.6***	.	***0.0***	***3.4***	
Aortic valve stenosis	22	<5	32	<5	<5	58	
	2.6	.	***1.6***	.	.	***1.8***	
Atrial septal defect	85	15	226	22	0	362	1
	10.2	***9.6***	***11.5***	***8.5***	***0.0***	***11.1***	
Atrioventricular septal defect (Endocardial cushion defect)	37	9	77	10	<5	143	
	4.5	***5.8***	***3.9***	***3.9***	.	***4.4***	
Biliary atresia	<5	<5	8	<5	0	17	
	.	.	***0.4***	.	***0.0***	***0.5***	
Bladder exstrophy	0	<5	0	<5	0	<5	
	0.0	.	***0.0***	.	***0.0***	.	
Choanal atresia	<5	0	<5	0	0	8	
	.	***0.0***	.	***0.0***	***0.0***	***0.2***	
Cleft lip alone	27	<5	47	<5	0	96	2
	3.3	.	***2.4***	.	***0.0***	***2.9***	
Cleft lip with cleft palate	36	<5	129	7	<5	189	2
	4.3	.	***6.6***	***2.7***	.	***5.8***	
Cleft palate alone	27	<5	68	<5	<5	115	2, 3
	3.3	.	***3.5***	.	.	***3.5***	
Cloacal exstrophy	<5	0	0	0	0	<5	
	.	***0.0***	***0.0***	***0.0***	***0.0***	.	
Coarctation of the aorta	49	7	101	5	0	173	
	5.9	***4.5***	***5.1***	***1.9***	***0.0***	***5.3***	
Common truncus (truncus arteriosus)	<5	0	5	0	0	10	
	.	***0.0***	***0.3***	***0.0***	***0.0***	***0.3***	
Congenital cataract	13	<5	19	<5	0	39	
	1.6	.	***1.0***	.	***0.0***	***1.2***	
Craniosynostosis	38	0	75	<5	0	118	
	4.6	***0.0***	***3.8***	.	***0.0***	***3.6***	
Diaphragmatic hernia	22	<5	40	6	0	75	
	2.6	.	***2.0***	***2.3***	***0.0***	***2.3***	
Double outlet right ventricle	15	<5	44	6	<5	72	
	1.8	.	***2.2***	***2.3***	.	***2.2***	
Ebstein anomaly	8	0	12	<5	0	22	
	1.0	***0.0***	***0.6***	.	***0.0***	***0.7***	
Encephalocele	<5	0	16	<5	<5	26	
	.	***0.0***	***0.8***	.	.	***0.8***	
Esophageal atresia/tracheoesophageal fistula	20	<5	35	<5	0	63	4
	2.4	.	***1.8***	.	***0.0***	***1.9***	
Gastroschisis	46	<5	114	12	<5	202	
	5.5	.	***5.8***	***4.6***	.	***6.2***	
Holoprosencephaly	<5	<5	24	0	0	39	
	.	.	***1.2***	***0.0***	***0.0***	***1.2***	
Hypoplastic left heart syndrome	23	<5	36	<5	0	78	
	2.8	.	***1.8***	.	***0.0***	***2.4***	
Hypospadias*	74	6	71	<5	<5	168	5
	17.3	***7.6***	***7.1***	.	.	***10.1***	
Interrupted aortic arch	<5	0	<5	0	0	8	
	.	***0.0***	.	***0.0***	***0.0***	***0.2***	
Limb deficiencies (reduction defects)	20	<5	57	<5	0	94	
	2.4	.	***2.9***	.	***0.0***	***2.9***	
Omphalocele	11	<5	25	0	<5	52	
	1.3	.	***1.3***	***0.0***	.	***1.6***	
Pulmonary valve atresia	6	<5	31	5	<5	49	
	0.7	.	***1.6***	***1.9***	.	***1.5***	

California

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Rectal and large intestinal atresia/stenosis	25	<5	69	<5	0	117	6
	3.0	**.**	***3.5***	**.**	***0.0***	***3.6***	
Renal agenesis/hypoplasia	<5	0	19	<5	0	27	7
	.	***0.0***	***1.0***	**.**	***0.0***	***0.8***	
Single ventricle	5	<5	17	<5	0	25	
	0.6	**.**	***0.9***	**.**	***0.0***	***0.8***	
Small intestinal atresia/stenosis	20	7	94	<5	<5	137	
	2.4	***4.5***	***4.8***	**.**	**.**	***4.2***	
Spina bifida without anencephalus	32	<5	81	<5	<5	130	
	3.9	**.**	***4.1***	**.**	**.**	***4.0***	
Tetralogy of Fallot	29	<5	61	<5	0	102	
	3.5	**.**	***3.1***	**.**	***0.0***	***3.1***	
Total anomalous pulmonary venous connection	12	<5	43	<5	<5	64	
	1.4	**.**	***2.2***	**.**	**.**	***2.0***	
Dextro-transposition of great arteries (d-TGA)	18	<5	37	<5	0	63	
	2.2	**.**	***1.9***	**.**	***0.0***	***1.9***	
Tricuspid valve atresia	5	0	13	<5	0	21	
	0.6	***0.0***	***0.7***	**.**	***0.0***	***0.6***	
Trisomy 13	6	<5	17	0	<5	44	
	0.7	**.**	***0.9***	***0.0***	**.**	***1.3***	
Trisomy 18	19	<5	45	<5	0	118	
	2.3	**.**	***2.3***	**.**	***0.0***	***3.6***	
Trisomy 21 (Down syndrome)	94	22	302	16	0	470	
	11.3	***14.1***	***15.4***	***6.2***	***0.0***	***14.4***	
Total live births	**83019**	**15608**	**196676**	**25899**	**2032**	**326993**	
Male live births	**42719**	**7855**	**99891**	**13283**	**1018**	**166645**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

California

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Trisomy 13	21	9	44	
	0.7	***2.3***	***1.3***	
Trisomy 18	38	38	118	
	1.3	***9.8***	***3.6***	
Trisomy 21 (Down syndrome)	221	234	470	
	7.7	***60.1***	***14.4***	
Total live births	**288004**	**38918**	**326993**	

**Total includes unknown maternal age

Notes

1.Data for this condition include only cases confirmed by physician review or echo or cath or surgery or autopsy. If the defect is a component of another major heart malformation it is not counted.
2.Data for this condition exclude cases where holoprosencephaly is present.
3.Data for this condition do not include submucous cleft and bifid uvula.
4.Data for this condition do not include isolated tracheoesophageal fistula.
5.Data for this condition include only 2nd and 3rd degree cases.
6.Data for this condition do not include anal stenosis.
7.Data for this condition do not include unilateral renal agenesis/hypoplasia.

General comments

-<5 indicates cell size suppressed to protect confidentiality or to indicate case count <5.
-Cases with single gene disorders are not included in this report. Cases with chromosomal defects other than trisomy 13, 18 and 21 are not included in this report.
-Stillbirths greater than or equal to 20 weeks are included for all defect types.
-Terminations are included for all gestational ages.

Colorado

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	22	5	16	1	1	50	
	1.1	***3.5***	***1.7***	***0.9***	***4.4***	***1.5***	
Anophthalmia/microphthalmia	32	3	23	0	1	60	
	1.6	***2.1***	***2.4***	***0.0***	***4.4***	***1.8***	
Anotia/microtia	31	6	46	4	1	93	
	1.5	***4.2***	***4.9***	***3.5***	***4.4***	***2.8***	
Aortic valve stenosis	64	4	34	2	0	107	
	3.1	***2.8***	***3.6***	***1.8***	***0.0***	***3.2***	
Atrial septal defect	2536	266	1302	162	36	4470	
	124.1	***187.2***	***137.9***	***142.1***	***157.7***	***134.0***	
Atrioventricular septal defect (Endocardial cushion defect)	78	12	38	4	2	150	
	3.8	***8.4***	***4.0***	***3.5***	***8.8***	***4.5***	
Biliary atresia	28	1	13	0	0	47	
	1.4	***0.7***	***1.4***	***0.0***	***0.0***	***1.4***	
Bladder exstrophy	9	0	3	0	0	13	
	0.4	***0.0***	***0.3***	***0.0***	***0.0***	***0.4***	
Choanal atresia	44	3	19	0	0	73	
	2.2	***2.1***	***2.0***	***0.0***	***0.0***	***2.2***	
Cleft lip alone	82	5	47	2	0	145	
	4.0	***3.5***	***5.0***	***1.8***	***0.0***	***4.3***	
Cleft lip with cleft palate	144	8	98	7	3	321	
	7.0	***5.6***	***10.4***	***6.1***	***13.1***	***9.6***	
Cleft palate alone	164	8	68	7	3	282	
	8.0	***5.6***	***7.2***	***6.1***	***13.1***	***8.5***	
Cloacal exstrophy	138	13	78	8	2	256	
	6.8	***9.2***	***8.3***	***8.7***	***8.8***	***7.7***	
Clubfoot	367	15	180	18	7	626	
	18.0	***10.6***	***19.1***	***15.8***	***30.7***	***18.8***	
Coarctation of the aorta	193	18	77	4	0	304	
	9.4	***12.7***	***8.2***	***3.5***	***0.0***	***9.1***	
Common truncus (truncus arteriosus)	19	1	12	0	1	33	
	0.9	***0.7***	***1.3***	***0.0***	***4.4***	***1.0***	
Congenital cataract	45	2	22	2	1	75	
	2.2	***1.4***	***2.3***	***1.8***	***4.4***	***2.2***	
Congenital posterior urethral valves	44	8	19	3	0	92	
	2.2	***5.6***	***2.0***	***2.6***	***0.0***	***2.8***	
Deletion 22q11.2	24	4	15	0	0	53	
	1.2	***2.8***	***1.6***	***0.0***	***0.0***	***1.6***	
Diaphragmatic hernia	45	5	23	1	0	80	
	2.2	***3.5***	***2.4***	***0.9***	***0.0***	***2.4***	
Double outlet right ventricle	22	4	19	3	0	57	
	1.1	***2.8***	***2.0***	***2.6***	***0.0***	***1.7***	
Ebstein anomaly	30	0	8	1	0	42	
	1.5	***0.0***	***0.8***	***0.9***	***0.0***	***1.3***	
Encephalocele	13	3	14	2	0	36	
	0.6	***2.1***	***1.5***	***1.8***	***0.0***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	96	5	42	3	1	157	
	4.7	***3.5***	***4.4***	***2.6***	***4.4***	***4.7***	
Gastroschisis	77	4	53	3	2	152	
	3.8	***2.8***	***5.6***	***2.6***	***8.8***	***4.6***	
Holoprosencephaly	10	1	15	1	0	33	
	0.5	***0.7***	***1.6***	***0.9***	***0.0***	***1.0***	
Hypoplastic left heart syndrome	55	3	28	0	0	94	
	2.7	***2.1***	***3.0***	***0.0***	***0.0***	***2.8***	
Hypospadias*	1429	108	361	43	18	2051	
	136.2	***148.7***	***74.6***	***74.8***	***151.5***	***119.9***	
Interrupted aortic arch	20	5	6	0	0	33	
	1.0	***3.5***	***0.6***	***0.0***	***0.0***	***1.0***	
Limb deficiencies (reduction defects)	82	6	51	1	0	162	
	4.0	***4.2***	***5.4***	***0.9***	***0.0***	***4.9***	

Colorado

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	39	3	22	1	1	80	
	1.9	***2.1***	***2.3***	***0.9***	***4.4***	***2.4***	
Pulmonary valve atresia and stenosis	127	13	64	8	3	228	
	6.2	***9.2***	***6.8***	***7.0***	***13.1***	***6.8***	
Pulmonary valve atresia	37	10	21	2	0	74	
	1.8	***7.0***	***2.2***	***1.8***	***0.0***	***2.2***	
Rectal and large intestinal atresia/stenosis	94	14	46	10	3	194	
	4.6	***9.9***	***4.9***	***8.8***	***13.1***	***5.8***	
Renal agenesis/hypoplasia	105	15	48	5	3	202	
	5.1	***10.6***	***5.1***	***4.4***	***13.1***	***6.1***	
Single ventricle	24	1	8	2	1	38	
	1.2	***0.7***	***0.8***	***1.8***	***4.4***	***1.1***	
Small intestinal atresia/stenosis	109	7	69	6	3	198	
	5.3	***4.9***	***7.3***	***5.3***	***13.1***	***5.9***	
Spina bifida without anencephalus	51	2	40	1	1	126	
	2.5	***1.4***	***4.2***	***0.9***	***4.4***	***3.8***	
Tetralogy of Fallot	63	6	36	4	1	120	
	3.1	***4.2***	***3.8***	***3.5***	***4.4***	***3.6***	
Total anomalous pulmonary venous connection	13	1	17	1	0	33	
	0.6	***0.7***	***1.8***	***0.9***	***0.0***	***1.0***	
Transposition of the great arteries (TGA)	50	4	19	5	0	80	
	2.4	***2.8***	***2.0***	***4.4***	***0.0***	***2.4***	
Dextro-transposition of great arteries (d-TGA)	44	4	20	5	0	75	
	2.2	***2.8***	***2.1***	***4.4***	***0.0***	***2.2***	
Tricuspid valve atresia and stenosis	29	6	11	1	0	48	
	1.4	***4.2***	***1.2***	***0.9***	***0.0***	***1.4***	
Tricuspid valve atresia	28	6	11	1	0	47	
	1.4	***4.2***	***1.2***	***0.9***	***0.0***	***1.4***	
Trisomy 13	19	4	15	2	0	80	
	0.9	***2.8***	***1.6***	***1.8***	***0.0***	***2.4***	
Trisomy 18	38	6	28	10	0	182	
	1.9	***4.2***	***3.0***	***8.8***	***0.0***	***5.5***	
Trisomy 21 (Down syndrome)	280	32	183	18	4	796	
	13.7	***22.5***	***19.4***	***15.8***	***17.5***	***23.9***	
Turner syndrome†	19	2	21	3	0	59	
	1.9	***2.9***	***4.6***	***5.3***	***0.0***	***3.6***	
Ventricular septal defect	985	91	550	56	19	1802	
	48.2	***64.1***	***58.2***	***49.1***	***83.2***	***54.0***	
Total live births §	**204336**	**14207**	**94439**	**11404**	**2283**	**333572**	
Male live births	**104924**	**7265**	**48399**	**5749**	**1188**	**171088**	
Female live births	**99408**	**6940**	**46038**	**5654**	**1095**	**162475**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Colorado

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	137	4	152	
	5.0	***0.7***	***4.6***	
Trisomy 13	27	13	80	
	1.0	***2.3***	***2.4***	
Trisomy 18	47	36	182	
	1.7	***6.3***	***5.5***	
Trisomy 21 (Down syndrome)	257	265	796	
	9.3	***46.3***	***23.9***	
Total live births	**276337**	**57178**	**333572**	

**Total includes unknown maternal age

Delaware

Birth Defects Counts and Prevalence 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	5	1	2	0	0	8	
	2.0	***0.8***	***3.5***	***0.0***	***0.0***	***1.8***	
Anophthalmia/microphthalmia	6	3	4	0	0	13	
	2.4	***2.5***	***7.0***	***0.0***	***0.0***	***2.9***	
Anotia/microtia	12	4	6	1	0	23	
	4.9	***3.3***	***10.5***	***4.7***	***0.0***	***5.1***	
Aortic valve stenosis	6	2	1	0	0	9	
	2.4	***1.7***	***1.7***	***0.0***	***0.0***	***2.0***	
Atrial septal defect	69	25	23	3	0	121	1
	28.1	***20.8***	***40.1***	***14.0***	***0.0***	***27.0***	
Atrioventricular septal defect (Endocardial cushion defect)	16	8	3	0	0	27	
	6.5	***6.6***	***5.2***	***0.0***	***0.0***	***6.0***	
Biliary atresia	1	2	0	0	0	3	
	0.4	***1.7***	***0.0***	***0.0***	***0.0***	***0.7***	
Bladder exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Choanal atresia	3	4	2	0	0	9	
	1.2	***3.3***	***3.5***	***0.0***	***0.0***	***2.0***	
Cleft lip alone	6	2	1	1	0	10	
	2.4	***1.7***	***1.7***	***4.7***	***0.0***	***2.2***	
Cleft lip with cleft palate	14	5	7	1	0	28	
	5.7	***4.2***	***12.2***	***4.7***	***0.0***	***6.2***	
Cleft palate alone	17	6	4	0	0	27	2
	6.9	***5.0***	***7.0***	***0.0***	***0.0***	***6.0***	
Cloacal exstrophy	1	0	0	0	0	1	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Clubfoot	37	14	11	4	0	66	
	15.1	***11.6***	***19.2***	***18.6***	***0.0***	***14.7***	
Coarctation of the aorta	21	2	7	2	0	32	3
	8.6	***1.7***	***12.2***	***9.3***	***0.0***	***7.1***	
Common truncus (truncus arteriosus)	1	0	1	0	0	2	
	0.4	***0.0***	***1.7***	***0.0***	***0.0***	***0.4***	
Congenital cataract	10	3	3	1	0	17	
	4.1	***2.5***	***5.2***	***4.7***	***0.0***	***3.8***	
Congenital posterior urethral valves	3	4	0	1	0	8	4
	1.2	***3.3***	***0.0***	***4.7***	***0.0***	***1.8***	
Craniosynostosis	16	5	5	0	0	26	
	6.5	***4.2***	***8.7***	***0.0***	***0.0***	***5.8***	
Deletion 22q11.2	2	2	0	0	0	4	
	0.8	***1.7***	***0.0***	***0.0***	***0.0***	***0.9***	
Diaphragmatic hernia	5	0	1	1	0	7	
	2.0	***0.0***	***1.7***	***4.7***	***0.0***	***1.6***	
Double outlet right ventricle	2	1	3	0	0	6	
	0.8	***0.8***	***5.2***	***0.0***	***0.0***	***1.3***	
Ebstein anomaly	2	1	0	0	0	3	
	1.1	***1.1***	***0.0***	***0.0***	***0.0***	***0.9***	
Encephalocele	1	2	2	0	0	5	
	0.4	***1.7***	***3.5***	***0.0***	***0.0***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	2	1	2	0	0	5	
	0.8	***0.8***	***3.5***	***0.0***	***0.0***	***1.1***	
Gastroschisis	19	12	3	0	0	34	
	7.7	***10.0***	***5.2***	***0.0***	***0.0***	***7.6***	
Holoprosencephaly	2	3	2	0	0	7	
	0.8	***2.5***	***3.5***	***0.0***	***0.0***	***1.6***	
Hypoplastic left heart syndrome	10	5	6	0	1	22	
	4.1	***4.2***	***10.5***	***0.0***	***119.0***	***4.9***	
Hypospadias*	131	45	13	10	0	200	
	104.8	***73.4***	***44.3***	***90.3***	***0.0***	***87.4***	
Limb deficiencies (reduction defects)	13	13	4	2	0	32	5
	5.3	***10.8***	***7.0***	***9.3***	***0.0***	***7.1***	

Delaware

Birth Defects Counts and Prevalence 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	3	4	2	0	0	9	
	1.2	***3.3***	***3.5***	***0.0***	***0.0***	***2.0***	
Pulmonary valve atresia and stenosis	31	21	10	0	1	63	6
	12.6	***17.4***	***17.4***	***0.0***	***119.0***	***14.0***	
Pulmonary valve atresia	10	4	4	0	0	18	
	4.1	***3.3***	***7.0***	***0.0***	***0.0***	***4.0***	
Rectal and large intestinal atresia/stenosis	12	1	2	0	0	15	
	4.9	***0.8***	***3.5***	***0.0***	***0.0***	***3.3***	
Renal agenesis/hypoplasia	22	5	5	0	0	32	
	9.0	***4.2***	***8.7***	***0.0***	***0.0***	***7.1***	
Single ventricle	4	0	1	0	0	5	
	1.6	***0.0***	***1.7***	***0.0***	***0.0***	***1.1***	
Small intestinal atresia/stenosis	7	4	3	0	0	14	
	2.9	***3.3***	***5.2***	***0.0***	***0.0***	***3.1***	
Spina bifida without anencephalus	6	1	0	0	0	7	7
	2.4	***0.8***	***0.0***	***0.0***	***0.0***	***1.6***	
Tetralogy of Fallot	7	3	1	3	0	14	8
	2.9	***2.5***	***1.7***	***14.0***	***0.0***	***3.1***	
Total anomalous pulmonary venous connection	4	0	2	0	0	6	
	2.2	***0.0***	***4.6***	***0.0***	***0.0***	***1.8***	
Transposition of the great arteries (TGA)	8	2	3	1	0	14	
	3.3	***1.7***	***5.2***	***4.7***	***0.0***	***3.1***	
Dextro-transposition of great arteries (d-TGA)	6	2	2	1	0	11	
	2.4	***1.7***	***3.5***	***4.7***	***0.0***	***2.5***	
Tricuspid valve atresia and stenosis	4	7	1	0	0	12	
	1.6	***5.8***	***1.7***	***0.0***	***0.0***	***2.7***	
Trisomy 13	4	1	2	1	0	8	
	1.6	***0.8***	***3.5***	***4.7***	***0.0***	***1.8***	
Trisomy 18	11	3	4	1	0	19	
	4.5	***2.5***	***7.0***	***4.7***	***0.0***	***4.2***	
Trisomy 21 (Down syndrome)	33	12	5	5	0	56	
	13.5	***10.0***	***8.7***	***23.3***	***0.0***	***12.5***	
Turner syndrome†	7	0	2	0	0	9	
	5.8	***0.0***	***7.1***	***0.0***	***0.0***	***4.1***	
Ventricular septal defect	209	79	56	18	0	364	9
	85.2	***65.6***	***97.6***	***83.7***	***0.0***	***81.1***	
Total live births	**24531**	**12039**	**5736**	**2150**	**84**	**44869**	
Male live births	**12498**	**6129**	**2935**	**1108**	**43**	**22876**	
Female live births	**12033**	**5910**	**2801**	**1042**	**41**	**21993**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

Delaware

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	33	1	34	
	8.6	***1.6***	***7.6***	
Trisomy 13	6	2	8	
	1.6	***3.2***	***1.8***	
Trisomy 18	8	11	19	
	2.1	***17.4***	***4.2***	
Trisomy 21 (Down syndrome)	28	28	56	
	7.3	***44.4***	***12.5***	
Total live births	**38562**	**6307**	**44869**	

**Total includes unknown maternal age

Notes

1.Data for this condition include atrial septal fenestrations. Data exclude atrial septal defects that self-close (not present after a month), which are considered patent foramen ovales.
2.Data for this condition include Pierre Robin anomalies with cleft palate.
3.Data for this condition include interrupted aortic arch.
4.Data for this condition limited to cases where surgical intervention is required.
5.Data for this condition include complex hand anomalies, adactyly, and syndactyly.
6.Data for this condition exclude peripheral, branch, trivial, or limited cases.
7.Data for this condition exclude spina bifida occulta.
8.Data for this condition include ventricular septal defect with overriding aorta.
9.Data for this condition include probable cases if the defect was found prenatally and the fetus died without a confirmatory autopsy.

General comments

-All chromosomal defects require a cytogenetics report.
-All heart defects require an echocardiogram report. Trivial or limited defects are excluded. State did not perform CCHD screening in 2009 and 2010.
-Fetal deaths (including terminations) are included if the fetus weighed 350 grams or greater or 20 weeks or more gestation. State does not distinguish spontaneous terminations from elective terminations - stillbirths, miscarriages, and terminations are reported together.

Florida

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	39	21	19	0	0	80	
	0.8	***0.9***	***0.6***	***0.0***	***0.0***	***0.7***	
Anophthalmia/microphthalmia	42	24	37	<5	0	104	
	0.9	***1.0***	***1.2***	***.***	***0.0***	***1.0***	
Anotia/microtia	27	9	45	7	0	92	
	0.6	***0.4***	***1.5***	***2.2***	***0.0***	***0.9***	
Aortic valve stenosis	73	17	32	<5	<5	131	
	1.5	***0.7***	***1.1***	***.***	***.***	***1.2***	
Atrial septal defect	4884	3079	3995	284	23	12581	
	103.0	***128.8***	***134.8***	***89.9***	***155.3***	***117.7***	
Atrioventricular septal defect (Endocardial cushion defect)	210	119	100	16	<5	460	1
	4.4	***5.0***	***3.4***	***5.1***	***.***	***4.3***	
Biliary atresia	38	37	17	<5	0	97	
	0.8	***1.5***	***0.6***	***.***	***0.0***	***0.9***	
Bladder exstrophy	12	6	5	0	0	23	
	0.3	***0.3***	***0.2***	***0.0***	***0.0***	***0.2***	
Choanal atresia	84	35	57	5	<5	186	
	1.8	***1.5***	***1.9***	***1.6***	***.***	***1.7***	
Cleft lip alone	126	35	52	<5	0	226	
	2.7	***1.5***	***1.8***	***.***	***0.0***	***2.1***	
Cleft lip with cleft palate	278	81	134	18	<5	524	
	5.9	***3.4***	***4.5***	***5.7***	***.***	***4.9***	
Cleft palate alone	316	98	143	20	0	592	
	6.7	***4.1***	***4.8***	***6.3***	***0.0***	***5.5***	
Cloacal exstrophy	308	163	203	14	<5	714	
	6.5	***6.8***	***6.8***	***4.4***	***.***	***6.7***	
Clubfoot	764	248	366	39	<5	1451	
	16.1	***10.4***	***12.3***	***12.3***	***.***	***13.6***	
Coarctation of the aorta	386	153	177	19	<5	760	
	8.1	***6.4***	***6.0***	***6.0***	***.***	***7.1***	
Common truncus (truncus arteriosus)	37	20	18	<5	0	79	
	0.8	***0.8***	***0.6***	***.***	***0.0***	***0.7***	
Congenital cataract	84	32	31	<5	0	153	
	1.8	***1.3***	***1.0***	***.***	***0.0***	***1.4***	
Congenital posterior urethral valves	66	60	27	<5	0	159	
	1.4	***2.5***	***0.9***	***.***	***0.0***	***1.5***	
Deletion 22q11.2	21	5	7	0	0	33	
	0.4	***0.2***	***0.2***	***0.0***	***0.0***	***0.3***	
Diaphragmatic hernia	163	79	89	7	<5	352	
	3.4	***3.3***	***3.0***	***2.2***	***.***	***3.3***	
Double outlet right ventricle	110	65	73	9	<5	270	
	2.3	***2.7***	***2.5***	***2.8***	***.***	***2.5***	
Ebstein anomaly	36	12	13	<5	<5	67	
	0.8	***0.5***	***0.4***	***.***	***.***	***0.6***	
Encephalocele	35	32	24	<5	0	94	
	0.7	***1.3***	***0.8***	***.***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	123	53	63	5	<5	250	
	2.6	***2.2***	***2.1***	***1.6***	***.***	***2.3***	
Gastroschisis	304	67	130	11	<5	522	2
	6.4	***2.8***	***4.4***	***3.5***	***.***	***4.9***	
Holoprosencephaly	215	132	130	16	0	505	
	4.5	***5.5***	***4.4***	***5.1***	***0.0***	***4.7***	
Hypoplastic left heart syndrome	156	95	71	8	0	337	
	3.3	***4.0***	***2.4***	***2.5***	***0.0***	***3.2***	
Hypospadias*	2153	859	836	89	<5	4041	
	88.5	***70.6***	***55.2***	***54.7***	***.***	***73.9***	
Interrupted aortic arch	26	15	22	<5	0	68	
	0.5	***0.6***	***0.7***	***.***	***0.0***	***0.6***	
Limb deficiencies (reduction defects)	189	89	98	15	<5	399	
	4.0	***3.7***	***3.3***	***4.7***	***.***	***3.7***	

Florida

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	99	73	39	<5	0	217	2
	2.1	***3.1***	***1.3***	***.***	***0.0***	***2.0***	
Pulmonary valve atresia and stenosis	407	320	290	23	0	1066	
	8.6	***13.4***	***9.8***	***7.3***	***0.0***	***10.0***	
Pulmonary valve atresia	65	45	51	<5	0	170	
	1.4	***1.9***	***1.7***	***.***	***0.0***	***1.6***	
Rectal and large intestinal atresia/stenosis	182	119	141	7	<5	471	
	3.8	***5.0***	***4.8***	***2.2***	***.***	***4.4***	
Renal agenesis/hypoplasia	272	141	145	11	<5	582	
	5.7	***5.9***	***4.9***	***3.5***	***.***	***5.4***	
Single ventricle	51	47	37	6	0	145	
	1.1	***2.0***	***1.2***	***1.9***	***0.0***	***1.4***	
Small intestinal atresia/stenosis	251	129	139	22	0	552	
	5.3	***5.4***	***4.7***	***7.0***	***0.0***	***5.2***	
Spina bifida without anencephalus	167	54	81	10	0	315	
	3.5	***2.3***	***2.7***	***3.2***	***0.0***	***2.9***	
Tetralogy of Fallot	257	131	118	16	<5	543	
	5.4	***5.5***	***4.0***	***5.1***	***.***	***5.1***	
Total anomalous pulmonary venous connection	39	33	29	<5	0	106	
	0.8	***1.4***	***1.0***	***.***	***0.0***	***1.0***	
Transposition of the great arteries (TGA)	162	42	59	<5	<5	277	
	3.4	***1.8***	***2.0***	***.***	***.***	***2.6***	
Dextro-transposition of great arteries (d-TGA)	137	34	52	<5	<5	236	
	2.9	***1.4***	***1.8***	***.***	***.***	***2.2***	
Tricuspid valve atresia and stenosis	44	38	25	<5	0	114	3
	0.9	***1.6***	***0.8***	***.***	***0.0***	***1.1***	
Trisomy 13	51	33	23	0	0	108	
	1.1	***1.4***	***0.8***	***0.0***	***0.0***	***1.0***	
Trisomy 18	82	65	57	6	0	219	
	1.7	***2.7***	***1.9***	***1.9***	***0.0***	***2.0***	
Trisomy 21 (Down syndrome)	640	303	413	53	<5	1457	
	13.5	***12.7***	***13.9***	***16.8***	***.***	***13.6***	
Turner syndrome†	33	14	24	0	0	73	
	1.4	***1.2***	***1.7***	***0.0***	***0.0***	***1.4***	
Ventricular septal defect	2980	1365	2088	180	9	6805	4
	62.8	***57.1***	***70.4***	***57.0***	***60.8***	***63.7***	
Total live births §	**474163**	**238974**	**296401**	**31592**	**1481**	**1068594**	
Male live births	**243409**	**121602**	**151482**	**16279**	**776**	**546952**	
Female live births	**230751**	**117366**	**144916**	**15312**	**705**	**521627**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births. Excludes male phenotype.
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Florida

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	508	14	522	2
	5.6	***0.9***	***4.9***	
Trisomy 13	71	37	108	
	0.8	***2.3***	***1.0***	
Trisomy 18	118	101	219	
	1.3	***6.2***	***2.0***	
Trisomy 21 (Down syndrome)	741	716	1457	
	8.2	***44.3***	***13.6***	
Total live births	**906777**	**161778**	**1068594**	

**Total includes unknown maternal age

Notes
1.Data for this condition include canal type atrioventricular septal defect.
2.Data for this condition may differ from previous reports due to coding system changes.
3.Data for this condition include congenital tricuspid stenosis.
4.Data for this condition include probable cases.

Georgia (Metropolitan Atlanta Congenital Defects Program)

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	15	21	15	0	0	65	
	2.5	***2.4***	***3.3***	***0.0***	***0.0***	***3.0***	
Anophthalmia/microphthalmia	9	11	3	2	0	29	
	1.5	***1.3***	***0.7***	***1.4***	***0.0***	***1.3***	
Anotia/microtia	10	10	20	3	0	46	
	1.6	***1.1***	***4.3***	***2.0***	***0.0***	***2.1***	
Aortic valve stenosis	13	5	9	0	0	31	
	2.1	***0.6***	***2.0***	***0.0***	***0.0***	***1.4***	
Atrial septal defect	75	136	51	13	0	323	
	12.3	***15.5***	***11.1***	***8.8***	***0.0***	***14.7***	
Atrioventricular septal defect (Endocardial cushion defect)	37	65	17	3	1	144	
	6.1	***7.4***	***3.7***	***2.0***	***67.6***	***6.5***	
Biliary atresia	3	3	1	0	1	12	
	0.5	***0.3***	***0.2***	***0.0***	***67.6***	***0.5***	
Bladder exstrophy	3	2	0	0	0	6	
	0.5	***0.2***	***0.0***	***0.0***	***0.0***	***0.3***	
Choanal atresia	5	9	3	0	0	18	
	0.8	***1.0***	***0.7***	***0.0***	***0.0***	***0.8***	
Cleft lip alone	23	22	10	10	0	71	
	3.8	***2.5***	***2.2***	***6.8***	***0.0***	***3.2***	
Cleft lip with cleft palate	33	31	24	12	0	116	
	5.4	***3.5***	***5.2***	***8.1***	***0.0***	***5.3***	
Cleft palate alone	31	37	23	10	0	111	
	5.1	***4.2***	***5.0***	***6.8***	***0.0***	***5.0***	
Cloacal exstrophy	1	1	0	1	0	3	
	0.2	***0.1***	***0.0***	***0.7***	***0.0***	***0.1***	
Clubfoot	93	134	61	14	1	337	
	15.3	***15.3***	***13.2***	***9.5***	***67.6***	***15.3***	
Coarctation of the aorta	44	41	24	5	0	129	
	7.2	***4.7***	***5.2***	***3.4***	***0.0***	***5.9***	
Common truncus (truncus arteriosus)	4	5	2	2	0	14	
	0.7	***0.6***	***0.4***	***1.4***	***0.0***	***0.6***	
Congenital cataract	11	19	10	2	0	43	
	1.8	***2.2***	***2.2***	***1.4***	***0.0***	***2.0***	
Congenital posterior urethral valves	5	20	11	2	0	50	
	0.8	***2.3***	***2.4***	***1.4***	***0.0***	***2.3***	
Craniosynostosis	32	20	10	1	1	83	
	5.3	***2.3***	***2.2***	***0.7***	***67.6***	***3.8***	
Deletion 22q11.2	4	7	2	0	0	20	
	0.7	***0.8***	***0.4***	***0.0***	***0.0***	***0.9***	
Diaphragmatic hernia	15	24	16	2	0	75	
	2.5	***2.7***	***3.5***	***1.4***	***0.0***	***3.4***	
Double outlet right ventricle	12	20	11	3	0	51	
	2.0	***2.3***	***2.4***	***2.0***	***0.0***	***2.3***	
Ebstein anomaly	0	4	4	2	0	11	
	0.0	***0.5***	***0.9***	***1.4***	***0.0***	***0.5***	
Encephalocele	2	7	4	3	1	25	
	0.3	***0.8***	***0.9***	***2.0***	***67.6***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	21	18	7	0	0	51	
	3.4	***2.1***	***1.5***	***0.0***	***0.0***	***2.3***	
Gastroschisis	23	28	22	3	0	86	
	3.8	***3.2***	***4.8***	***2.0***	***0.0***	***3.9***	
Holoprosencephaly	19	20	9	5	0	62	
	3.1	***2.3***	***2.0***	***3.4***	***0.0***	***2.8***	
Hypoplastic left heart syndrome	20	20	7	6	0	60	
	3.3	***2.3***	***1.5***	***4.1***	***0.0***	***2.7***	
Hypospadias*	244	305	71	24	3	727	
	77.8	***68.4***	***30.2***	***32.1***	***411.0***	***64.7***	
Interrupted aortic arch	4	3	0	0	0	11	
	0.7	***0.3***	***0.0***	***0.0***	***0.0***	***0.5***	

Georgia (Metropolitan Atlanta Congenital Defects Program)

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	21	44	20	1	0	100	
	3.4	***5.0***	***4.3***	***0.7***	***0.0***	***4.5***	
Omphalocele	18	35	9	3	1	84	
	3.0	***4.0***	***2.0***	***2.0***	***67.6***	***3.8***	
Pulmonary valve atresia and stenosis	47	67	31	8	1	181	
	7.7	***7.7***	***6.7***	***5.4***	***67.6***	***8.2***	
Pulmonary valve atresia	14	22	13	2	0	61	
	2.3	***2.5***	***2.8***	***1.4***	***0.0***	***2.8***	
Rectal and large intestinal atresia/stenosis	29	26	26	7	0	97	
	4.8	***3.0***	***5.6***	***4.7***	***0.0***	***4.4***	
Renal agenesis/hypoplasia	48	62	20	10	1	160	
	7.9	***7.1***	***4.3***	***6.8***	***67.6***	***7.3***	
Single ventricle	3	11	9	2	0	30	
	0.5	***1.3***	***2.0***	***1.4***	***0.0***	***1.4***	
Small intestinal atresia/stenosis	21	33	13	4	0	80	
	3.4	***3.8***	***2.8***	***2.7***	***0.0***	***3.6***	
Spina bifida without anencephalus	30	29	22	2	0	94	
	4.9	***3.3***	***4.8***	***1.4***	***0.0***	***4.3***	
Tetralogy of Fallot	37	37	8	6	0	103	
	6.1	***4.2***	***1.7***	***4.1***	***0.0***	***4.7***	
Total anomalous pulmonary venous connection	6	6	9	5	0	29	
	1.0	***0.7***	***2.0***	***3.4***	***0.0***	***1.3***	
Transposition of the great arteries (TGA)	30	24	13	0	0	74	
	4.9	***2.7***	***2.8***	***0.0***	***0.0***	***3.4***	
Dextro-transposition of great arteries (d-TGA)	28	18	7	0	0	59	
	4.6	***2.1***	***1.5***	***0.0***	***0.0***	***2.7***	
Tricuspid valve atresia and stenosis	11	16	9	3	0	47	
	1.8	***1.8***	***2.0***	***2.0***	***0.0***	***2.1***	
Tricuspid valve atresia	7	6	3	2	0	20	
	1.1	***0.7***	***0.7***	***1.4***	***0.0***	***0.9***	
Trisomy 13	17	22	4	1	0	54	
	2.8	***2.5***	***0.9***	***0.7***	***0.0***	***2.5***	
Trisomy 18	41	38	14	6	1	125	
	6.7	***4.3***	***3.0***	***4.1***	***67.6***	***5.7***	
Trisomy 21 (Down syndrome)	148	127	92	22	1	459	
	24.3	***14.5***	***20.0***	***14.9***	***67.6***	***20.9***	
Turner syndrome†	16	20	2	5	0	51	
	5.4	***4.7***	***0.9***	***6.9***	***0.0***	***4.7***	
Ventricular septal defect	388	369	245	52	5	1192	
	63.7	***42.2***	***53.2***	***35.3***	***337.8***	***54.2***	
Total live births §	**60878**	**87532**	**46079**	**14749**	**148**	**220109**	
Male live births	**31347**	**44578**	**23497**	**7473**	**73**	**112425**	
Female live births	**29531**	**42950**	**22582**	**7275**	**75**	**107678**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Georgia (Metropolitan Atlanta Congenital Defects Program)

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	77	5	86	
	4.4	***1.1***	***3.9***	
Trisomy 13	33	21	54	
	1.9	***4.5***	***2.5***	
Trisomy 18	41	79	125	
	2.4	***17.0***	***5.7***	
Trisomy 21 (Down syndrome)	203	237	459	
	11.7	***50.9***	***20.9***	
Total live births	**173567**	**46535**	**220109**	

**Total includes unknown maternal age

General comments

-Cases for which the date of delivery was unknown are included in the year of their last prenatal test.
-Data include pregnancies with a prenatal diagnosis at any gestational age for which the outcome could not be documented from available data sources.
-Elective terminations include all gestational ages.
-Live births include gestational ages greater than or equal to 20 weeks.
-Prior to 2012 data include 5 counties. Data for 2012-2013 include 3 of the 5 counties.
-Stillbirths include gestational ages greater than or equal to 20 weeks.

Hawaii

Birth Defects Counts and Prevalence 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	2	0	0	1	0	4	
	4.7	***0.0***	***0.0***	***0.7***	***0.0***	***2.1***	
Anotia/microtia	1	0	0	0	0	1	
	2.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Atrial septal defect	7	0	4	18	0	35	
	16.3	***0.0***	***134.2***	***13.3***	***0.0***	***18.5***	
Atrioventricular septal defect (Endocardial cushion defect)	1	0	1	3	0	5	
	2.3	***0.0***	***33.6***	***2.2***	***0.0***	***2.6***	
Biliary atresia	1	0	0	2	0	3	
	2.3	***0.0***	***0.0***	***1.5***	***0.0***	***1.6***	
Bladder exstrophy	1	0	0	0	0	1	
	2.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Choanal atresia	1	0	0	0	0	1	
	2.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Cleft lip alone	3	0	2	8	0	14	
	7.0	***0.0***	***67.1***	***5.9***	***0.0***	***7.4***	
Cleft lip with cleft palate	1	0	0	7	0	9	
	2.3	***0.0***	***0.0***	***5.2***	***0.0***	***4.7***	
Cleft palate alone	2	0	0	4	0	7	
	4.7	***0.0***	***0.0***	***3.0***	***0.0***	***3.7***	
Coarctation of the aorta	1	0	0	3	0	4	
	2.3	***0.0***	***0.0***	***2.2***	***0.0***	***2.1***	
Ebstein anomaly	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.7***	***0.0***	***0.5***	
Encephalocele	0	0	0	2	0	2	
	0.0	***0.0***	***0.0***	***1.5***	***0.0***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	1	0	0	3	0	5	
	2.3	***0.0***	***0.0***	***2.2***	***0.0***	***2.6***	
Gastroschisis	2	0	0	9	0	12	
	4.7	***0.0***	***0.0***	***6.7***	***0.0***	***6.3***	
Hypoplastic left heart syndrome	0	0	0	2	0	3	
	0.0	***0.0***	***0.0***	***1.5***	***0.0***	***1.6***	
Hypospadias*	6	0	2	40	0	54	
	27.6	***0.0***	***123.5***	***57.8***	***0.0***	***56.0***	
Omphalocele	0	0	1	3	0	4	
	0.0	***0.0***	***33.6***	***2.2***	***0.0***	***2.1***	
Pulmonary valve atresia and stenosis	5	0	1	5	0	12	
	11.7	***0.0***	***33.6***	***3.7***	***0.0***	***6.3***	
Pulmonary valve atresia	0	0	0	2	0	2	
	0.0	***0.0***	***0.0***	***1.5***	***0.0***	***1.1***	
Rectal and large intestinal atresia/stenosis	3	0	0	8	0	12	
	7.0	***0.0***	***0.0***	***5.9***	***0.0***	***6.3***	
Renal agenesis/hypoplasia	1	0	0	6	0	8	
	2.3	***0.0***	***0.0***	***4.4***	***0.0***	***4.2***	
Spina bifida without anencephalus	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***0.7***	***0.0***	***0.5***	
Tetralogy of Fallot	1	0	0	1	0	2	
	2.3	***0.0***	***0.0***	***0.7***	***0.0***	***1.1***	
Total anomalous pulmonary venous connection	0	0	0	2	0	2	
	0.0	***0.0***	***0.0***	***1.5***	***0.0***	***1.1***	
Transposition of the great arteries (TGA)	0	1	1	6	0	8	
	0.0	***20.0***	***33.6***	***4.4***	***0.0***	***4.2***	
Tricuspid valve atresia and stenosis	0	0	1	3	0	4	
	0.0	***0.0***	***33.6***	***2.2***	***0.0***	***2.1***	
Tricuspid valve atresia	0	0	1	3	0	4	
	0.0	***0.0***	***33.6***	***2.2***	***0.0***	***2.1***	
Trisomy 13	0	0	0	2	0	2	
	0.0	***0.0***	***0.0***	***1.5***	***0.0***	***1.1***	
Trisomy 18	3	0	1	6	0	15	
	7.0	***0.0***	***33.6***	***4.4***	***0.0***	***7.9***	

Hawaii

Birth Defects Counts and Prevalence 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Trisomy 21 (Down syndrome)	5	0	2	14	0	29	
	11.7	***0.0***	***67.1***	***10.3***	***0.0***	***15.3***	
Turner syndrome†	1	0	0	1	0	2	
	4.7	***0.0***	***0.0***	***1.5***	***0.0***	***2.2***	
Ventricular septal defect	8	0	4	29	0	50	
	18.7	***0.0***	***134.2***	***21.4***	***0.0***	***26.4***	
Total live births §	**4282**	**501**	**298**	**13532**	**237**	**18965**	
Male live births	**2172**	**251**	**162**	**6918**	**113**	**9645**	
Female live births	**2110**	**250**	**136**	**6614**	**124**	**9263**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Hawaii

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2012 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	12	0	12	
	7.7	***0.0***	***6.3***	
Trisomy 13	1	1	2	
	0.6	***3.0***	***1.1***	
Trisomy 18	8	7	15	
	5.2	***20.7***	***7.9***	
Trisomy 21 (Down syndrome)	13	16	29	
	8.4	***47.3***	***15.3***	
Total live births	**15497**	**3382**	**18965**	

**Total includes unknown maternal age

General comments

-Fetal deaths are defined as baby born dead (without heart rate or respiration) during or after 18th gestation week; includes babies that died during childbirth.

-Terminations limited to 20 weeks gestation and 350 gms.

Illinois

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	55	15	46	3	0	122	
	1.3	***1.1***	***2.6***	***0.6***	***0.0***	***1.5***	
Anophthalmia/microphthalmia	62	19	32	5	0	118	
	1.4	***1.4***	***1.8***	***1.0***	***0.0***	***1.5***	
Anotia/microtia	54	9	73	13	0	149	
	1.2	***0.6***	***4.1***	***2.7***	***0.0***	***1.9***	
Aortic valve stenosis	58	8	28	4	0	98	
	1.3	***0.6***	***1.6***	***0.8***	***0.0***	***1.2***	
Atrial septal defect	1115	404	490	132	7	2149	
	25.8	***29.0***	***27.7***	***27.2***	***46.6***	***26.7***	
Atrioventricular septal defect (Endocardial cushion defect)	223	89	82	13	0	408	1
	5.2	***6.4***	***4.6***	***2.7***	***0.0***	***5.1***	
Biliary atresia	5	6	5	2	0	18	
	0.1	***0.4***	***0.3***	***0.4***	***0.0***	***0.2***	
Bladder exstrophy	14	2	5	1	0	23	
	0.3	***0.1***	***0.3***	***0.2***	***0.0***	***0.3***	
Choanal atresia	53	17	19	4	0	93	
	1.2	***1.2***	***1.1***	***0.8***	***0.0***	***1.2***	
Cleft lip alone	173	42	54	18	2	289	
	4.0	***3.0***	***3.0***	***3.7***	***13.3***	***3.6***	
Cleft lip with cleft palate	194	49	119	31	1	394	
	4.5	***3.5***	***6.7***	***6.4***	***6.7***	***4.9***	
Cleft palate alone	251	55	101	21	0	429	
	5.8	***3.9***	***5.7***	***4.3***	***0.0***	***5.3***	
Cloacal exstrophy	5	3	1	1	0	10	
	0.1	***0.2***	***0.1***	***0.2***	***0.0***	***0.1***	
Clubfoot	287	71	132	19	0	511	
	6.6	***5.1***	***7.5***	***3.9***	***0.0***	***6.4***	
Coarctation of the aorta	159	39	85	14	1	298	
	3.7	***2.8***	***4.8***	***2.9***	***6.7***	***3.7***	
Common truncus (truncus arteriosus)	29	7	12	1	0	50	
	0.7	***0.5***	***0.7***	***0.2***	***0.0***	***0.6***	
Congenital cataract	28	20	7	2	0	57	
	0.6	***1.4***	***0.4***	***0.4***	***0.0***	***0.7***	
Congenital posterior urethral valves	23	16	9	1	0	49	
	0.5	***1.1***	***0.5***	***0.2***	***0.0***	***0.6***	
Craniosynostosis	35	8	21	1	0	65	
	0.8	***0.6***	***1.2***	***0.2***	***0.0***	***0.8***	
Deletion 22q11.2	35	18	12	2	0	67	
	0.8	***1.3***	***0.7***	***0.4***	***0.0***	***0.8***	
Diaphragmatic hernia	123	32	37	10	1	205	
	2.8	***2.3***	***2.1***	***2.1***	***6.7***	***2.6***	
Double outlet right ventricle	58	27	36	12	1	134	
	1.3	***1.9***	***2.0***	***2.5***	***6.7***	***1.7***	
Ebstein anomaly	25	3	16	2	0	46	
	0.6	***0.2***	***0.9***	***0.4***	***0.0***	***0.6***	
Encephalocele	19	14	27	4	0	65	
	0.4	***1.0***	***1.5***	***0.8***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	113	25	48	9	0	195	
	2.6	***1.8***	***2.7***	***1.9***	***0.0***	***2.4***	
Gastroschisis	157	63	91	2	0	313	
	3.6	***4.5***	***5.1***	***0.4***	***0.0***	***3.9***	
Holoprosencephaly	32	9	25	0	1	70	
	0.7	***0.6***	***1.4***	***0.0***	***6.7***	***0.9***	
Hypoplastic left heart syndrome	72	34	40	6	1	153	
	1.7	***2.4***	***2.3***	***1.2***	***6.7***	***1.9***	
Hypospadias*	1444	362	252	111	7	2176	
	64.9	***51.0***	***27.9***	***44.5***	***92.1***	***52.9***	
Interrupted aortic arch	21	15	6	0	0	42	
	0.5	***1.1***	***0.3***	***0.0***	***0.0***	***0.5***	

Illinois

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	209	80	92	17	0	400	
	4.8	***5.7***	***5.2***	***3.5***	***0.0***	***5.0***	
Omphalocele	87	32	24	6	1	150	
	2.0	***2.3***	***1.4***	***1.2***	***6.7***	***1.9***	
Pulmonary valve atresia and stenosis	130	67	68	12	0	277	
	3.0	***4.8***	***3.8***	***2.5***	***0.0***	***3.4***	
Pulmonary valve atresia	28	14	19	3	0	64	
	0.6	***1.0***	***1.1***	***0.6***	***0.0***	***0.8***	
Rectal and large intestinal atresia/stenosis	159	54	68	15	3	299	
	3.7	***3.9***	***3.8***	***3.1***	***20.0***	***3.7***	
Renal agenesis/hypoplasia	235	84	105	31	0	459	
	5.4	***6.0***	***5.9***	***6.4***	***0.0***	***5.7***	
Single ventricle	16	9	3	2	0	30	
	0.4	***0.6***	***0.2***	***0.4***	***0.0***	***0.4***	
Small intestinal atresia/stenosis	78	29	52	9	1	169	
	1.8	***2.1***	***2.9***	***1.9***	***6.7***	***2.1***	
Spina bifida without anencephalus	141	34	64	11	0	251	
	3.3	***2.4***	***3.6***	***2.3***	***0.0***	***3.1***	
Tetralogy of Fallot	128	49	65	22	2	267	
	3.0	***3.5***	***3.7***	***4.5***	***13.3***	***3.3***	
Total anomalous pulmonary venous connection	25	8	20	4	0	57	
	0.6	***0.6***	***1.1***	***0.8***	***0.0***	***0.7***	
Transposition of the great arteries (TGA)	105	26	50	9	0	190	
	2.4	***1.9***	***2.8***	***1.9***	***0.0***	***2.4***	
Dextro-transposition of great arteries (d-TGA)	87	25	39	8	0	159	
	2.0	***1.8***	***2.2***	***1.6***	***0.0***	***2.0***	
Tricuspid valve atresia and stenosis	95	36	58	5	1	195	2
	2.2	***2.6***	***3.3***	***1.0***	***6.7***	***2.4***	
Tricuspid valve atresia	22	9	15	1	0	47	3
	0.5	***0.6***	***0.8***	***0.2***	***0.0***	***0.6***	
Trisomy 13	52	17	25	4	1	101	
	1.2	***1.2***	***1.4***	***0.8***	***6.7***	***1.3***	
Trisomy 18	100	29	62	6	1	206	
	2.3	***2.1***	***3.5***	***1.2***	***6.7***	***2.6***	
Trisomy 21 (Down syndrome)	553	127	335	43	4	1066	
	12.8	***9.1***	***18.9***	***8.9***	***26.6***	***13.3***	
Turner syndrome†	41	9	19	1	0	71	
	1.9	***1.3***	***2.2***	***0.4***	***0.0***	***1.8***	
Ventricular septal defect	1864	473	836	185	16	3375	4
	43.1	***33.9***	***47.2***	***38.1***	***106.5***	***42.0***	
Total live births §	**432818**	**139374**	**177101**	**48572**	**1502**	**803766**	
Male live births	**222380**	**70995**	**90233**	**24955**	**760**	**411565**	
Female live births	**210429**	**68371**	**86861**	**23617**	**742**	**392177**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births. Excludes male phenotype.
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Illinois

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	299	9	313	
	4.4	***0.7***	***3.9***	
Trisomy 13	70	25	101	
	1.0	***1.9***	***1.3***	
Trisomy 18	122	51	206	
	1.8	***3.9***	***2.6***	
Trisomy 21 (Down syndrome)	503	547	1066	
	7.5	***42.0***	***13.3***	
Total live births	**673520**	**130184**	**803766**	

**Total includes unknown maternal age

Notes
1.Data for this condition include inlet ventricular septal defects including common atrioventricular canal type ventricular septal defect.
2.Data for this condition include tricuspid stenosis or hypoplasia.
3.Data for this condition exclude tricuspid stenosis or hypoplasia.
4.Data for this condition exclude probable cases, and inlet ventricular septal defects including common atrioventricular canal type ventricular septal defects.

General comments
-Data for all conditions include live births from birth to age 2 years and fetal deaths (these include stillbirths of 20 weeks gestation or more, and miscarriages where the families chose to hold funerals).

Iowa

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	42	3	5	1	0	52	
	2.6	***3.4***	***3.2***	***1.7***	***0.0***	***2.7***	
Anophthalmia/microphthalmia	26	0	4	1	1	33	
	1.6	***0.0***	***2.6***	***1.7***	***11.4***	***1.7***	
Anotia/microtia	29	1	10	1	0	42	
	1.8	***1.1***	***6.4***	***1.7***	***0.0***	***2.2***	
Aortic valve stenosis	47	1	3	2	0	54	
	2.9	***1.1***	***1.9***	***3.4***	***0.0***	***2.8***	
Atrial septal defect	497	39	49	11	0	605	
	30.9	***43.9***	***31.2***	***18.5***	***0.0***	***31.2***	
Atrioventricular septal defect (Endocardial cushion defect)	93	11	13	4	0	121	
	5.8	***12.4***	***8.3***	***6.7***	***0.0***	***6.2***	
Biliary atresia	7	1	1	0	0	9	
	0.4	***1.1***	***0.6***	***0.0***	***0.0***	***0.5***	
Bladder exstrophy	7	0	0	0	0	7	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Choanal atresia	28	0	0	0	0	28	1
	1.7	***0.0***	***0.0***	***0.0***	***0.0***	***1.4***	
Cleft lip alone	59	4	6	2	0	71	
	3.7	***4.5***	***3.8***	***3.4***	***0.0***	***3.7***	
Cleft lip with cleft palate	92	4	10	5	0	111	
	5.7	***4.5***	***6.4***	***8.4***	***0.0***	***5.7***	
Cleft palate alone	120	4	9	5	0	139	
	7.5	***4.5***	***5.7***	***8.4***	***0.0***	***7.2***	
Cloacal exstrophy	2	0	1	0	0	3	
	0.1	***0.0***	***0.6***	***0.0***	***0.0***	***0.2***	
Clubfoot	269	12	26	11	1	320	
	16.7	***13.5***	***16.6***	***18.5***	***11.4***	***16.5***	
Coarctation of the aorta	95	2	10	1	0	109	
	5.9	***2.3***	***6.4***	***1.7***	***0.0***	***5.6***	
Common truncus (truncus arteriosus)	6	0	1	0	0	7	
	0.4	***0.0***	***0.6***	***0.0***	***0.0***	***0.4***	
Congenital cataract	64	2	4	1	2	74	
	4.0	***2.3***	***2.6***	***1.7***	***22.7***	***3.8***	
Congenital posterior urethral valves	19	1	0	2	1	23	
	1.2	***1.1***	***0.0***	***3.4***	***11.4***	***1.2***	
Craniosynostosis	119	4	12	4	0	139	
	7.4	***4.5***	***7.7***	***6.7***	***0.0***	***7.2***	
Deletion 22q11.2	22	1	1	0	0	24	
	1.4	***1.1***	***0.6***	***0.0***	***0.0***	***1.2***	
Diaphragmatic hernia	44	3	4	2	0	55	
	2.7	***3.4***	***2.6***	***3.4***	***0.0***	***2.8***	
Double outlet right ventricle	30	6	6	1	0	46	
	1.9	***6.8***	***3.8***	***1.7***	***0.0***	***2.4***	
Ebstein anomaly	13	1	0	1	0	15	
	0.8	***1.1***	***0.0***	***1.7***	***0.0***	***0.8***	
Encephalocele	16	1	0	0	0	17	
	1.0	***1.1***	***0.0***	***0.0***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	53	1	2	1	0	57	
	3.3	***1.1***	***1.3***	***1.7***	***0.0***	***2.9***	
Gastroschisis	90	8	18	1	1	120	
	5.6	***9.0***	***11.5***	***1.7***	***11.4***	***6.2***	
Holoprosencephaly	26	4	3	0	0	33	
	1.6	***4.5***	***1.9***	***0.0***	***0.0***	***1.7***	
Hypoplastic left heart syndrome	42	5	6	2	0	55	
	2.6	***5.6***	***3.8***	***3.4***	***0.0***	***2.8***	
Hypospadias*	519	21	26	8	0	577	
	63.2	***46.0***	***33.3***	***26.1***	***0.0***	***58.3***	
Interrupted aortic arch	10	0	0	0	0	10	
	0.6	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	

Iowa

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	96	4	12	5	0	117	2
	6.0	***4.5***	***7.7***	***8.4***	***0.0***	***6.0***	
Omphalocele	35	3	6	1	0	48	
	2.2	***3.4***	***3.8***	***1.7***	***0.0***	***2.5***	
Pulmonary valve atresia and stenosis	215	15	15	11	0	258	
	13.4	***16.9***	***9.6***	***18.5***	***0.0***	***13.3***	
Pulmonary valve atresia	19	1	2	0	0	22	
	1.2	***1.1***	***1.3***	***0.0***	***0.0***	***1.1***	
Rectal and large intestinal atresia/stenosis	67	5	14	1	0	87	
	4.2	***5.6***	***8.9***	***1.7***	***0.0***	***4.5***	
Renal agenesis/hypoplasia	91	4	7	5	0	108	
	5.7	***4.5***	***4.5***	***8.4***	***0.0***	***5.6***	
Single ventricle	8	3	1	0	0	12	
	0.5	***3.4***	***0.6***	***0.0***	***0.0***	***0.6***	
Small intestinal atresia/stenosis	53	3	10	1	0	69	
	3.3	***3.4***	***6.4***	***1.7***	***0.0***	***3.6***	
Spina bifida without anencephalus	61	3	15	0	0	80	
	3.8	***3.4***	***9.6***	***0.0***	***0.0***	***4.1***	
Tetralogy of Fallot	62	4	4	3	1	74	
	3.9	***4.5***	***2.6***	***5.0***	***11.4***	***3.8***	
Total anomalous pulmonary venous connection	13	0	4	1	0	18	
	0.8	***0.0***	***2.6***	***1.7***	***0.0***	***0.9***	
Transposition of the great arteries (TGA)	44	4	6	3	0	58	
	2.7	***4.5***	***3.8***	***5.0***	***0.0***	***3.0***	
Dextro-transposition of great arteries (d-TGA)	39	3	5	3	0	50	
	2.4	***3.4***	***3.2***	***5.0***	***0.0***	***2.6***	
Tricuspid valve atresia and stenosis	34	3	4	0	1	42	
	2.1	***3.4***	***2.6***	***0.0***	***11.4***	***2.2***	
Tricuspid valve atresia	4	1	1	0	0	6	
	0.2	***1.1***	***0.6***	***0.0***	***0.0***	***0.3***	
Trisomy 13	24	2	2	0	0	28	
	1.5	***2.3***	***1.3***	***0.0***	***0.0***	***1.4***	
Trisomy 18	50	3	4	3	0	62	
	3.1	***3.4***	***2.6***	***5.0***	***0.0***	***3.2***	
Trisomy 21 (Down syndrome)	210	12	30	7	0	265	
	13.1	***13.5***	***19.1***	***11.8***	***0.0***	***13.7***	
Turner syndrome†	44	1	3	0	0	49	
	5.6	***2.3***	***3.8***	***0.0***	***0.0***	***5.2***	
Ventricular septal defect	897	38	83	23	3	1053	
	55.8	***42.8***	***52.9***	***38.6***	***34.1***	***54.3***	
Total live births	**160706**	**8875**	**15681**	**5953**	**880**	**194062**	
Male live births	**82112**	**4562**	**7801**	**3069**	**453**	**98988**	
Female live births	**78594**	**4313**	**7880**	**2884**	**427**	**95074**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

Iowa

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	117	3	120	
	6.8	***1.4***	***6.2***	
Trisomy 13	21	7	28	
	1.2	***3.4***	***1.4***	
Trisomy 18	39	23	62	
	2.3	***11.0***	***3.2***	
Trisomy 21 (Down syndrome)	145	120	265	
	8.4	***57.5***	***13.7***	
Total live births	**173179**	**20876**	**194062**	

**Total includes unknown maternal age

Notes
1.Data for this condition exclude choanal stenosis.
2.Data for this condition exclude not otherwise specified and unspecified limb reductions

General comments
-Data for all conditions exclude probable/possible cases.
-Fetal deaths defined as 20 or more weeks gestation and/or 350 grams or greater.
-Terminations include all gestational ages.
-Unspecified non-live births includes spontaneous abortions.

Kansas

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	37	<5	13	<5	0	56	
	2.7	***.***	***4.1***	***.***	***0.0***	***2.9***	
Anophthalmia/microphthalmia	<5	0	0	0	0	<5	
	.	***0.0***	***0.0***	***0.0***	***0.0***	***.***	
Anotia/microtia	<5	0	<5	0	0	5	
	.	***0.0***	***.***	***0.0***	***0.0***	***0.3***	
Aortic valve stenosis	<5	0	<5	0	0	5	
	.	***0.0***	***.***	***0.0***	***0.0***	***0.3***	
Atrial septal defect	129	39	72	<5	<5	295	1
	9.3	***29.4***	***22.9***	***.***	***.***	***15.2***	
Atrioventricular septal defect (Endocardial cushion defect)	17	<5	<5	0	0	23	
	1.2	***.***	***.***	***0.0***	***0.0***	***1.2***	
Biliary atresia	<5	0	<5	<5	0	<5	
	.	***0.0***	***.***	***.***	***0.0***	***.***	
Bladder exstrophy	0	0	0	0	0	<5	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***.***	
Choanal atresia	<5	0	<5	0	0	8	
	.	***0.0***	***.***	***0.0***	***0.0***	***0.4***	
Cleft lip alone	11	<5	<5	<5	0	18	
	0.8	***.***	***.***	***.***	***0.0***	***0.9***	
Cleft lip with cleft palate	29	<5	13	0	0	50	
	2.1	***.***	***4.1***	***0.0***	***0.0***	***2.6***	
Cleft palate alone	55	5	23	<5	<5	92	
	4.0	***3.8***	***7.3***	***.***	***.***	***4.7***	
Cloacal exstrophy	21	<5	<5	<5	0	30	
	1.5	***.***	***.***	***.***	***0.0***	***1.5***	
Clubfoot	109	8	29	<5	0	164	
	7.9	***6.0***	***9.2***	***.***	***0.0***	***8.5***	
Coarctation of the aorta	12	0	<5	0	0	20	
	0.9	***0.0***	***.***	***0.0***	***0.0***	***1.0***	
Common truncus (truncus arteriosus)	<5	0	0	0	0	<5	
	.	***0.0***	***0.0***	***0.0***	***0.0***	***.***	
Congenital cataract	<5	0	<5	0	0	<5	
	.	***0.0***	***.***	***0.0***	***0.0***	***.***	
Congenital posterior urethral valves	<5	0	<5	0	0	5	
	.	***0.0***	***.***	***0.0***	***0.0***	***0.3***	
Craniosynostosis	<5	0	0	0	0	<5	
	.	***0.0***	***0.0***	***0.0***	***0.0***	***.***	
Diaphragmatic hernia	21	<5	13	<5	0	41	
	1.5	***.***	***4.1***	***.***	***0.0***	***2.1***	
Double outlet right ventricle	<5	<5	<5	0	0	10	
	.	***.***	***.***	***0.0***	***0.0***	***0.5***	
Ebstein anomaly	<5	0	<5	0	0	<5	
	.	***0.0***	***.***	***0.0***	***0.0***	***.***	
Encephalocele	<5	0	<5	0	0	6	
	.	***0.0***	***.***	***0.0***	***0.0***	***0.3***	
Esophageal atresia/tracheoesophageal fistula	11	<5	<5	0	0	18	
	0.8	***.***	***.***	***0.0***	***0.0***	***0.9***	
Gastroschisis	71	<5	14	0	0	98	
	5.1	***.***	***4.4***	***0.0***	***0.0***	***5.1***	
Holoprosencephaly	35	<5	13	<5	0	58	
	2.5	***.***	***4.1***	***.***	***0.0***	***3.0***	
Hypoplastic left heart syndrome	10	<5	<5	<5	0	21	
	0.7	***.***	***.***	***.***	***0.0***	***1.1***	
Hypospadias*	170	22	24	5	<5	237	
	24.0	***32.7***	***14.9***	***16.9***	***.***	***23.9***	
Interrupted aortic arch	0	<5	<5	0	0	<5	
	0.0	***.***	***.***	***0.0***	***0.0***	***.***	
Limb deficiencies (reduction defects)	36	8	16	<5	0	67	
	2.6	***6.0***	***5.1***	***.***	***0.0***	***3.5***	

Kansas

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	22	<5	13	<5	0	48	
	1.6	***.***	***4.1***	***.***	***0.0***	***2.5***	
Pulmonary valve atresia and stenosis	29	6	10	0	0	51	
	2.1	***4.5***	***3.2***	***0.0***	***0.0***	***2.6***	
Rectal and large intestinal atresia/stenosis	13	<5	14	<5	0	34	
	0.9	***.***	***4.4***	***.***	***0.0***	***1.8***	
Renal agenesis/hypoplasia	16	<5	6	0	0	28	
	1.2	***.***	***1.9***	***0.0***	***0.0***	***1.4***	
Single ventricle	0	0	<5	0	0	<5	
	0.0	***0.0***	***.***	***0.0***	***0.0***	***.***	
Small intestinal atresia/stenosis	23	0	5	<5	0	32	
	1.7	***0.0***	***1.6***	***.***	***0.0***	***1.6***	
Spina bifida without anencephalus	35	<5	15	<5	0	61	
	2.5	***.***	***4.8***	***.***	***0.0***	***3.1***	
Tetralogy of Fallot	13	0	5	<5	0	23	
	0.9	***0.0***	***1.6***	***.***	***0.0***	***1.2***	
Total anomalous pulmonary venous connection	<5	0	<5	0	0	6	
	.	***0.0***	***.***	***0.0***	***0.0***	***0.3***	
Transposition of the great arteries (TGA)	12	<5	<5	<5	0	18	
	0.9	***.***	***.***	***.***	***0.0***	***0.9***	
Tricuspid valve atresia and stenosis	<5	<5	<5	0	0	5	
	.	***.***	***.***	***0.0***	***0.0***	***0.3***	
Trisomy 13	8	<5	<5	0	0	15	
	0.6	***.***	***.***	***0.0***	***0.0***	***0.8***	
Trisomy 18	18	0	11	0	0	30	
	1.3	***0.0***	***3.5***	***0.0***	***0.0***	***1.5***	
Trisomy 21 (Down syndrome)	125	11	49	10	<5	217	
	9.0	***8.3***	***15.6***	***17.5***	***.***	***11.2***	
Turner syndrome†	6	0	<5	0	0	7	
	0.9	***0.0***	***.***	***0.0***	***0.0***	***0.7***	
Ventricular septal defect	153	12	84	9	<5	303	
	11.1	***9.0***	***26.7***	***15.7***	***.***	***15.6***	
Total live births	**138235**	**13271**	**31504**	**5727**	**962**	**193977**	
Male live births	**70753**	**6721**	**16072**	**2966**	**453**	**99151**	
Female live births	**67482**	**6550**	**15432**	**2761**	**509**	**94826**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births. Excludes male phenotype.
**Total includes unknown and other maternal race/ethnicity

Kansas

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	94	<5	98	
	5.4	**.**	***5.1***	
Trisomy 13	9	6	15	
	0.5	***2.9***	***0.8***	
Trisomy 18	17	13	30	
	1.0	***6.2***	***1.5***	
Trisomy 21 (Down syndrome)	121	95	217	
	7.0	***45.5***	***11.2***	
Total live births	**173096**	**20872**	**193977**	

**Total includes unknown maternal age

Notes
1.Data for this condition had a high number of unknown race/ethnicity cases.

General comments
-Data for conditions include live births and fetal deaths/stillbirths.
-Includes probable cases.
-Stillbirth means any complete expulsion or extraction from its mother of a human child the gestational age of which is not less than 20 completed weeks.

Kentucky

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	24	0	0	0	0	25	
	1.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.9***	
Anophthalmia/microphthalmia	15	1	0	0	0	16	
	0.6	***0.4***	***0.0***	***0.0***	***0.0***	***0.6***	
Anotia/microtia	9	1	2	0	0	14	
	0.4	***0.4***	***1.4***	***0.0***	***0.0***	***0.5***	
Aortic valve stenosis	32	3	2	0	0	40	
	1.4	***1.2***	***1.4***	***0.0***	***0.0***	***1.4***	
Atrial septal defect	4730	903	194	0	0	6092	
	204.5	***372.5***	***140.5***	***0.0***	***0.0***	***217.6***	
Atrioventricular septal defect (Endocardial cushion defect)	64	12	2	0	0	83	
	2.8	***5.0***	***1.4***	***0.0***	***0.0***	***3.0***	
Biliary atresia	5	1	0	0	0	7	
	0.2	***0.4***	***0.0***	***0.0***	***0.0***	***0.3***	
Bladder exstrophy	6	0	0	0	0	6	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	22	2	1	0	0	25	
	1.0	***0.8***	***0.7***	***0.0***	***0.0***	***0.9***	
Cleft lip alone	89	7	3	0	0	103	
	3.8	***2.9***	***2.2***	***0.0***	***0.0***	***3.7***	
Cleft lip with cleft palate	134	8	5	0	0	151	
	5.8	***3.3***	***3.6***	***0.0***	***0.0***	***5.4***	
Cleft palate alone	132	9	6	0	0	154	
	5.7	***3.7***	***4.3***	***0.0***	***0.0***	***5.5***	
Cloacal exstrophy	78	16	3	1	0	103	
	3.4	***6.6***	***2.2***	***3.5***	***0.0***	***3.7***	
Clubfoot	351	27	13	0	0	404	
	15.2	***11.1***	***9.4***	***0.0***	***0.0***	***14.4***	
Coarctation of the aorta	148	14	7	0	0	173	
	6.4	***5.8***	***5.1***	***0.0***	***0.0***	***6.2***	
Common truncus (truncus arteriosus)	14	4	0	0	0	18	
	0.6	***1.7***	***0.0***	***0.0***	***0.0***	***0.6***	
Congenital cataract	16	2	0	0	0	19	
	0.7	***0.8***	***0.0***	***0.0***	***0.0***	***0.7***	
Congenital posterior urethral valves	22	6	0	0	0	30	
	1.0	***2.5***	***0.0***	***0.0***	***0.0***	***1.1***	
Deletion 22q11.2	2	1	1	0	0	4	
	0.1	***0.4***	***0.7***	***0.0***	***0.0***	***0.1***	
Diaphragmatic hernia	60	10	2	0	0	76	
	2.6	***4.1***	***1.4***	***0.0***	***0.0***	***2.7***	
Double outlet right ventricle	58	10	1	0	0	73	
	2.5	***4.1***	***0.7***	***0.0***	***0.0***	***2.6***	
Ebstein anomaly	11	1	0	0	0	13	
	0.5	***0.4***	***0.0***	***0.0***	***0.0***	***0.5***	
Encephalocele	17	5	0	0	0	23	
	0.7	***2.1***	***0.0***	***0.0***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	47	1	3	0	0	52	
	2.0	***0.4***	***2.2***	***0.0***	***0.0***	***1.9***	
Gastroschisis	86	9	4	0	0	104	
	3.7	***3.7***	***2.9***	***0.0***	***0.0***	***3.7***	
Holoprosencephaly	91	9	5	0	0	109	
	3.9	***3.7***	***3.6***	***0.0***	***0.0***	***3.9***	
Hypoplastic left heart syndrome	62	9	2	0	0	75	
	2.7	***3.7***	***1.4***	***0.0***	***0.0***	***2.7***	
Hypospadias*	960	85	19	0	0	1091	
	80.6	***68.9***	***26.8***	***0.0***	***0.0***	***75.8***	
Interrupted aortic arch	6	2	0	0	0	10	
	0.3	***0.8***	***0.0***	***0.0***	***0.0***	***0.4***	
Limb deficiencies (reduction defects)	69	4	3	2	0	80	
	3.0	***1.7***	***2.2***	***7.0***	***0.0***	***2.9***	

Kentucky

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	31	2	1	0	0	34	
	1.3	***0.8***	***0.7***	***0.0***	***0.0***	***1.2***	
Pulmonary valve atresia and stenosis	171	17	6	0	0	206	
	7.4	***7.0***	***4.3***	***0.0***	***0.0***	***7.4***	
Pulmonary valve atresia	19	2	0	0	0	24	
	0.8	***0.8***	***0.0***	***0.0***	***0.0***	***0.9***	
Rectal and large intestinal atresia/stenosis	140	17	5	2	0	175	
	6.1	***7.0***	***3.6***	***7.0***	***0.0***	***6.3***	
Renal agenesis/hypoplasia	111	11	4	1	0	136	
	4.8	***4.5***	***2.9***	***3.5***	***0.0***	***4.9***	
Single ventricle	7	1	1	0	0	13	
	0.3	***0.4***	***0.7***	***0.0***	***0.0***	***0.5***	
Small intestinal atresia/stenosis	66	7	3	0	0	81	
	2.9	***2.9***	***2.2***	***0.0***	***0.0***	***2.9***	
Spina bifida without anencephalus	56	12	3	0	0	76	
	2.4	***5.0***	***2.2***	***0.0***	***0.0***	***2.7***	
Tetralogy of Fallot	87	11	4	0	0	109	
	3.8	***4.5***	***2.9***	***0.0***	***0.0***	***3.9***	
Total anomalous pulmonary venous connection	16	2	2	0	0	21	
	0.7	***0.8***	***1.4***	***0.0***	***0.0***	***0.8***	
Transposition of the great arteries (TGA)	58	5	0	0	0	63	
	2.5	***2.1***	***0.0***	***0.0***	***0.0***	***2.3***	
Dextro-transposition of great arteries (d-TGA)	48	4	0	0	0	52	
	2.1	***1.7***	***0.0***	***0.0***	***0.0***	***1.9***	
Tricuspid valve atresia and stenosis	22	2	0	0	0	25	
	1.0	***0.8***	***0.0***	***0.0***	***0.0***	***0.9***	
Trisomy 13	24	3	1	0	0	28	
	1.0	***1.2***	***0.7***	***0.0***	***0.0***	***1.0***	
Trisomy 18	35	3	1	0	0	41	
	1.5	***1.2***	***0.7***	***0.0***	***0.0***	***1.5***	
Trisomy 21 (Down syndrome)	241	26	17	0	0	302	
	10.4	***10.7***	***12.3***	***0.0***	***0.0***	***10.8***	
Turner syndrome†	22	1	1	0	0	24	
	2.0	***0.8***	***1.5***	***0.0***	***0.0***	***1.8***	
Ventricular septal defect	1098	141	57	0	0	1365	1
	47.5	***58.2***	***41.3***	***0.0***	***0.0***	***48.8***	
Total live births §	**231339**	**24240**	**13805**	**2860**	**288**	**279959**	
Male live births	**119108**	**12328**	**7089**	**1456**	**138**	**143993**	
Female live births	**112211**	**11910**	**6715**	**1404**	**150**	**135943**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Kentucky

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	101	3	104	
	4.0	***1.1***	***3.7***	
Trisomy 13	23	5	28	
	0.9	***1.8***	***1.0***	
Trisomy 18	24	17	41	
	1.0	***6.2***	***1.5***	
Trisomy 21 (Down syndrome)	217	78	302	
	8.7	***28.2***	***10.8***	
Total live births	**250257**	**27633**	**279959**	

**Total includes unknown maternal age

Notes
1.Data for this condition exclude inlet ventricular septal defect and common atrioventricular canal type ventricular septal defect.

General comments
-Fetal death defined as 20 weeks or more gestation or 350 grams or greater.

Louisiana

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	11	<5	<5	<5	0	17	
	1.1	***.***	***.***	***.***	***0.0***	***0.9***	
Anophthalmia/microphthalmia	8	5	0	0	0	13	
	0.8	***0.7***	***0.0***	***0.0***	***0.0***	***0.7***	
Anotia/microtia	0	<5	<5	0	0	<5	
	0.0	***.***	***.***	***0.0***	***0.0***	***.***	
Aortic valve stenosis	11	7	<5	0	0	19	
	1.1	***1.0***	***.***	***0.0***	***0.0***	***1.0***	
Atrial septal defect	336	252	40	8	<5	642	
	33.9	***35.6***	***35.5***	***25.0***	***.***	***34.4***	
Atrioventricular septal defect (Endocardial cushion defect)	38	27	<5	<5	0	69	
	3.8	***3.8***	***.***	***.***	***0.0***	***3.7***	
Biliary atresia	<5	<5	0	0	0	6	
	.	***.***	***0.0***	***0.0***	***0.0***	***0.3***	
Bladder exstrophy	5	<5	0	0	0	6	
	0.5	***.***	***0.0***	***0.0***	***0.0***	***0.3***	
Choanal atresia	14	<5	0	0	0	16	
	1.4	***.***	***0.0***	***0.0***	***0.0***	***0.9***	
Cleft lip alone	34	12	<5	<5	0	49	
	3.4	***1.7***	***.***	***.***	***0.0***	***2.6***	
Cleft lip with cleft palate	40	27	7	0	0	74	
	4.0	***3.8***	***6.2***	***0.0***	***0.0***	***4.0***	
Cleft palate alone	58	26	5	<5	0	90	
	5.9	***3.7***	***4.4***	***.***	***0.0***	***4.8***	
Clubfoot	<5	0	0	0	.	<5	
	.	***0.0***	***0.0***	***0.0***	***.***	***.***	
Coarctation of the aorta	42	22	<5	<5	0	67	
	4.2	***3.1***	***.***	***.***	***0.0***	***3.6***	
Common truncus (truncus arteriosus)	5	<5	<5	0	0	8	
	0.5	***.***	***.***	***0.0***	***0.0***	***0.4***	
Congenital cataract	5	10	0	0	0	15	
	0.5	***1.4***	***0.0***	***0.0***	***0.0***	***0.8***	
Congenital posterior urethral valves	20	17	<5	<5	0	40	
	2.0	***2.4***	***.***	***.***	***0.0***	***2.1***	
Deletion 22q11.2	<5	<5	0	<5	0	<5	
	.	***.***	***0.0***	***.***	***0.0***	***.***	
Diaphragmatic hernia	13	10	<5	0	0	25	
	1.3	***1.4***	***.***	***0.0***	***0.0***	***1.3***	
Double outlet right ventricle	12	7	<5	0	0	23	
	1.2	***1.0***	***.***	***0.0***	***0.0***	***1.2***	
Ebstein anomaly	5	<5	<5	<5	0	8	
	0.5	***.***	***.***	***.***	***0.0***	***0.4***	
Encephalocele	8	8	0	0	0	17	
	0.8	***1.1***	***0.0***	***0.0***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	11	8	<5	0	0	21	
	1.1	***1.1***	***.***	***0.0***	***0.0***	***1.1***	
Gastroschisis	12	6	0	0	0	18	
	1.2	***0.8***	***0.0***	***0.0***	***0.0***	***1.0***	
Holoprosencephaly	<5	0	0	0	0	<5	
	.	***0.0***	***0.0***	***0.0***	***0.0***	***.***	
Hypoplastic left heart syndrome	6	15	0	0	0	21	
	0.6	***2.1***	***0.0***	***0.0***	***0.0***	***1.1***	
Hypospadias*	421	182	21	8	5	641	
	83.1	***50.5***	***36.8***	***48.3***	***82.6***	***67.2***	
Interrupted aortic arch	<5	<5	0	0	0	<5	
	.	***.***	***0.0***	***0.0***	***0.0***	***.***	
Limb deficiencies (reduction defects)	23	23	<5	0	<5	50	
	2.3	***3.2***	***.***	***0.0***	***.***	***2.7***	
Omphalocele	9	16	0	<5	0	26	
	0.9	***2.3***	***0.0***	***.***	***0.0***	***1.4***	

Louisiana

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	38	32	<5	0	<5	74	
	3.8	***4.5***	***.***	***0.0***	***.***	***4.0***	
Pulmonary valve atresia	8	5	<5	0	0	14	
	0.8	***0.7***	***.***	***0.0***	***0.0***	***0.8***	
Rectal and large intestinal atresia/stenosis	33	22	<5	0	0	58	
	3.3	***3.1***	***.***	***0.0***	***0.0***	***3.1***	
Renal agenesis/hypoplasia	40	15	<5	0	<5	60	
	4.0	***2.1***	***.***	***0.0***	***.***	***3.2***	
Single ventricle	<5	<5	0	0	0	5	
	.	***.***	***0.0***	***0.0***	***0.0***	***0.3***	
Spina bifida without anencephalus	29	13	<5	0	0	43	
	2.9	***1.8***	***.***	***0.0***	***0.0***	***2.3***	
Tetralogy of Fallot	24	27	<5	<5	0	54	
	2.4	***3.8***	***.***	***.***	***0.0***	***2.9***	
Total anomalous pulmonary venous connection	0	<5	0	0	0	<5	
	0.0	***.***	***0.0***	***0.0***	***0.0***	***.***	
Transposition of the great arteries (TGA)	27	6	<5	0	0	36	
	2.7	***0.8***	***.***	***0.0***	***0.0***	***1.9***	
Dextro-transposition of great arteries (d-TGA)	18	5	<5	0	0	25	
	1.8	***0.7***	***.***	***0.0***	***0.0***	***1.3***	
Tricuspid valve atresia and stenosis	9	5	<5	0	<5	17	
	0.9	***0.7***	***.***	***0.0***	***.***	***0.9***	
Tricuspid valve atresia	5	5	<5	0	<5	12	
	0.5	***0.7***	***.***	***0.0***	***.***	***0.6***	
Trisomy 13	6	<5	<5	0	0	10	
	0.6	***.***	***.***	***0.0***	***0.0***	***0.5***	
Trisomy 18	21	8	<5	<5	0	31	
	2.1	***1.1***	***.***	***.***	***0.0***	***1.7***	
Trisomy 21 (Down syndrome)	101	57	14	5	0	177	
	10.2	***8.1***	***12.4***	***15.6***	***0.0***	***9.5***	
Turner syndrome†	6	<5	<5	0	0	9	
	1.2	***.***	***.***	***0.0***	***0.0***	***1.0***	
Ventricular septal defect	375	239	53	9	7	686	
	37.9	***33.8***	***47.1***	***28.1***	***60.9***	***36.8***	
Total live births §	**98988**	**70803**	**11257**	**3200**	**1150**	**186646**	
Male live births	**50647**	**36067**	**5708**	**1657**	**605**	**95318**	
Female live births	**48338**	**34736**	**5548**	**1543**	**545**	**91324**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births. Excludes male phenotype.
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Louisiana

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	94	<5	98	
	5.4	**.**	***5.1***	
Trisomy 13	9	6	15	
	0.5	***2.9***	***0.8***	
Trisomy 18	17	13	30	
	1.0	***6.2***	***1.5***	
Trisomy 21 (Down syndrome)	121	95	217	
	7.0	***45.5***	***11.2***	
Total live births	**173096**	**20872**	**193977**	

**Total includes unknown maternal age

General comments

-2009 birth defects data are provisional and include live births to Louisiana residents that occurred in 50/54 birth hospitals and covered 92 % of total births.
-2010 birth defects data are provisional and include only live births to Louisiana residents that occurred in 45/56 birth hospitals and covered 76 % of total births.
-2011 birth defects data are provisional and include only live births to Louisiana residents that occurred in 41/55 birth hospitals and covered 68 % of total births.
-2012 birth defects data are provisional and include only live births to Louisiana residents that occurred in 28/51 birth hospitals and covered 36 % of total births.
-2013 birth defects data are provisional and include only live births to Louisiana residents that occurred in 17/52 birth hospitals and covered 18 % of total births.
-All probable cases are included.
-Only live births with birth weight >= 350 grams or a gestational age >= 20 weeks are included in surveillance.

Maine

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	10	2	0	0	0	16	1
	1.7	***10.0***	***0.0***	***0.0***	***0.0***	***2.5***	
Anotia/microtia	3	0	0	0	0	4	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Aortic valve stenosis	1	0	0	0	0	1	2
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Atrial septal defect	38	0	2	1	1	43	2
	32.3	***0.0***	***116.3***	***41.0***	***86.2***	***33.7***	
Atrioventricular septal defect (Endocardial cushion defect)	3	0	0	0	0	3	2
	2.5	***0.0***	***0.0***	***0.0***	***0.0***	***2.3***	
Choanal atresia	5	0	0	0	0	5	3
	1.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Cleft lip alone	20	0	0	0	0	20	
	3.3	***0.0***	***0.0***	***0.0***	***0.0***	***3.1***	
Cleft lip with cleft palate	27	1	0	1	0	31	
	4.5	***5.0***	***0.0***	***8.8***	***0.0***	***4.8***	
Cleft palate alone	36	1	0	1	1	41	
	6.0	***5.0***	***0.0***	***8.8***	***17.0***	***6.3***	
Coarctation of the aorta	31	0	0	0	0	32	
	5.2	***0.0***	***0.0***	***0.0***	***0.0***	***4.9***	
Common truncus (truncus arteriosus)	3	0	0	0	0	3	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Congenital posterior urethral valves	36	1	0	2	0	40	2
	30.6	***22.6***	***0.0***	***82.0***	***0.0***	***31.3***	
Diaphragmatic hernia	1	0	0	0	0	1	2
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Double outlet right ventricle	4	0	0	0	0	4	4
	1.1	***0.0***	***0.0***	***0.0***	***0.0***	***1.0***	
Ebstein anomaly	1	0	0	0	0	1	2
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Encephalocele	5	0	0	1	0	6	
	0.8	***0.0***	***0.0***	***8.8***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	5	0	0	0	0	5	2
	4.2	***0.0***	***0.0***	***0.0***	***0.0***	***3.9***	
Gastroschisis	38	0	1	1	0	41	
	6.4	***0.0***	***10.0***	***8.8***	***0.0***	***6.3***	
Hypoplastic left heart syndrome	20	2	1	0	0	27	
	3.3	***10.0***	***10.0***	***0.0***	***0.0***	***4.2***	
Hypospadias*	202	7	3	4	3	226	
	65.7	***64.6***	***58.1***	***67.7***	***99.7***	***67.8***	
Interrupted aortic arch	1	0	0	0	0	1	4
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Limb deficiencies (reduction defects)	16	0	0	0	1	20	
	2.7	***0.0***	***0.0***	***0.0***	***17.0***	***3.1***	
Omphalocele	11	0	0	0	0	11	
	1.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.7***	
Pulmonary valve atresia and stenosis	25	1	0	1	0	27	5
	4.2	***5.0***	***0.0***	***8.8***	***0.0***	***4.2***	
Pulmonary valve atresia	4	1	0	0	0	5	
	0.7	***5.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Rectal and large intestinal atresia/stenosis	8	0	0	0	0	8	2
	6.8	***0.0***	***0.0***	***0.0***	***0.0***	***6.3***	
Renal agenesis/hypoplasia	8	1	0	0	0	9	2
	6.8	***22.6***	***0.0***	***0.0***	***0.0***	***7.0***	
Single ventricle	1	0	0	0	0	1	4
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Spina bifida without anencephalus	18	0	0	0	0	21	
	3.0	***0.0***	***0.0***	***0.0***	***0.0***	***3.2***	
Tetralogy of Fallot	27	0	0	0	0	28	
	4.5	***0.0***	***0.0***	***0.0***	***0.0***	***4.3***	

Maine

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Transposition of the great arteries (TGA)	19	1	0	1	0	22	
	3.2	***5.0***	***0.0***	***8.8***	***0.0***	***3.4***	
Tricuspid valve atresia	5	0	0	0	0	5	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Trisomy 13	2	0	0	0	0	2	2
	1.7	***0.0***	***0.0***	***0.0***	***0.0***	***1.6***	
Trisomy 18	2	0	0	0	0	2	2
	1.7	***0.0***	***0.0***	***0.0***	***0.0***	***1.6***	
Trisomy 21 (Down syndrome)	68	1	4	1	0	79	
	11.4	***5.0***	***40.2***	***8.8***	***0.0***	***12.2***	
Ventricular septal defect	29	0	1	0	0	32	2
	24.6	***0.0***	***58.1***	***0.0***	***0.0***	***25.0***	
Total live births	**59833**	**2007**	**996**	**1132**	**587**	**64718**	
Male live births	**30755**	**1084**	**516**	**591**	**301**	**33331**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

Maine

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	41	0	41	
	7.3	***0.0***	***6.3***	
Trisomy 13	2	0	2	2
	1.8	***0.0***	***1.6***	
Trisomy 18	2	0	2	2
	1.8	***0.0***	***1.6***	
Trisomy 21 (Down syndrome)	51	27	79	
	9.1	***30.7***	***12.2***	
Total live births	**55926**	**8792**	**64718**	

**Total includes unknown maternal age

Notes
1.Data for this condition include probable cases.
2.Data for this condition begin in 2013.
3.Data for this condition begin in 2011.
4.Data for this condition end in 2011.
5.Data for this condition include atresia only through 2010; data including stenosis begin in 2011.

General comments
-Fetal deaths are defined as deaths that occur at any gestational age.
-Termination data not available

Maryland

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	37	9	7	0	0	57	
	2.2	***0.7***	***1.3***	***0.0***	***0.0***	***1.6***	
Anophthalmia/microphthalmia	1	2	1	0	0	4	
	0.1	***0.2***	***0.2***	***0.0***	***0.0***	***0.1***	
Anotia/microtia	5	2	6	1	0	15	
	0.3	***0.2***	***1.2***	***0.4***	***0.0***	***0.4***	
Aortic valve stenosis	2	0	0	0	0	3	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Atrial septal defect	9	8	2	0	0	19	
	0.5	***0.7***	***0.4***	***0.0***	***0.0***	***0.5***	
Atrioventricular septal defect (Endocardial cushion defect)	6	7	1	0	0	15	
	0.4	***0.6***	***0.2***	***0.0***	***0.0***	***0.4***	
Biliary atresia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Bladder exstrophy	3	2	1	0	0	6	
	0.2	***0.2***	***0.2***	***0.0***	***0.0***	***0.2***	
Choanal atresia	5	2	1	0	0	9	
	0.3	***0.2***	***0.2***	***0.0***	***0.0***	***0.2***	
Cleft lip alone	61	15	2	5	0	93	
	3.7	***1.2***	***0.4***	***1.9***	***0.0***	***2.5***	
Cleft lip with cleft palate	84	26	19	6	0	139	
	5.0	***2.2***	***3.7***	***2.3***	***0.0***	***3.8***	
Cleft palate alone	82	26	12	6	0	143	
	4.9	***2.2***	***2.3***	***2.3***	***0.0***	***3.9***	
Cloacal exstrophy	2	0	0	0	0	2	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Clubfoot	96	48	17	5	1	178	
	5.8	***4.0***	***3.3***	***1.9***	***12.8***	***4.9***	
Coarctation of the aorta	10	3	2	1	0	20	
	0.6	***0.2***	***0.4***	***0.4***	***0.0***	***0.5***	
Common truncus (truncus arteriosus)	3	1	0	1	0	5	
	0.2	***0.1***	***0.0***	***0.4***	***0.0***	***0.1***	
Congenital cataract	1	1	0	0	0	3	
	0.1	***0.1***	***0.0***	***0.0***	***0.0***	***0.1***	
Congenital posterior urethral valves	5	3	0	1	0	9	
	0.3	***0.2***	***0.0***	***0.4***	***0.0***	***0.2***	
Craniosynostosis	5	3	1	0	0	9	
	0.3	***0.2***	***0.2***	***0.0***	***0.0***	***0.2***	
Deletion 22q11.2	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Diaphragmatic hernia	9	9	2	0	0	20	
	0.5	***0.7***	***0.4***	***0.0***	***0.0***	***0.5***	
Double outlet right ventricle	10	1	0	0	0	12	
	0.6	***0.1***	***0.0***	***0.0***	***0.0***	***0.3***	
Ebstein anomaly	4	1	1	0	0	7	
	0.2	***0.1***	***0.2***	***0.0***	***0.0***	***0.2***	
Encephalocele	7	7	1	1	0	16	
	0.4	***0.6***	***0.2***	***0.4***	***0.0***	***0.4***	
Esophageal atresia/tracheoesophageal fistula	23	12	5	2	0	48	
	1.4	***1.0***	***1.0***	***0.8***	***0.0***	***1.3***	
Gastroschisis	12	6	1	1	0	24	
	0.7	***0.5***	***0.2***	***0.4***	***0.0***	***0.7***	
Holoprosencephaly	12	10	5	0	0	27	
	0.7	***0.8***	***1.0***	***0.0***	***0.0***	***0.7***	
Hypoplastic left heart syndrome	13	4	0	3	0	24	
	0.8	***0.3***	***0.0***	***1.1***	***0.0***	***0.7***	
Hypospadias*	352	248	49	34	0	768	
	41.3	***40.6***	***18.5***	***25.0***	***0.0***	***41.0***	
Interrupted aortic arch	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	

Maryland

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	38	48	15	3	0	114	
	2.3	***4.0***	***2.9***	***1.1***	***0.0***	***3.1***	
Omphalocele	2	5	0	0	0	11	
	0.1	***0.4***	***0.0***	***0.0***	***0.0***	***0.3***	
Pulmonary valve atresia and stenosis	3	4	0	0	0	13	
	0.2	***0.3***	***0.0***	***0.0***	***0.0***	***0.4***	
Pulmonary valve atresia	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Rectal and large intestinal atresia/stenosis	21	19	5	4	0	56	
	1.3	***1.6***	***1.0***	***1.5***	***0.0***	***1.5***	
Renal agenesis/hypoplasia	20	20	2	3	0	51	
	1.2	***1.7***	***0.4***	***1.1***	***0.0***	***1.4***	
Single ventricle	5	7	0	0	0	20	
	0.3	***0.6***	***0.0***	***0.0***	***0.0***	***0.5***	
Small intestinal atresia/stenosis	12	10	1	0	0	27	
	0.7	***0.8***	***0.2***	***0.0***	***0.0***	***0.7***	
Spina bifida without anencephalus	55	17	8	2	0	85	
	3.3	***1.4***	***1.5***	***0.8***	***0.0***	***2.3***	
Tetralogy of Fallot	28	9	2	5	0	50	
	1.7	***0.7***	***0.4***	***1.9***	***0.0***	***1.4***	
Total anomalous pulmonary venous connection	1	0	0	0	0	2	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Transposition of the great arteries (TGA)	11	5	1	3	0	22	
	0.7	***0.4***	***0.2***	***1.1***	***0.0***	***0.6***	
Dextro-transposition of great arteries (d-TGA)	10	2	1	3	0	16	
	0.6	***0.2***	***0.2***	***1.1***	***0.0***	***0.4***	
Tricuspid valve atresia and stenosis	2	2	1	0	0	8	
	0.1	***0.2***	***0.2***	***0.0***	***0.0***	***0.2***	
Tricuspid valve atresia	1	0	1	0	0	2	
	0.1	***0.0***	***0.2***	***0.0***	***0.0***	***0.1***	
Trisomy 13	14	4	1	1	0	20	
	0.8	***0.3***	***0.2***	***0.4***	***0.0***	***0.5***	
Trisomy 18	25	9	9	2	0	49	
	1.5	***0.7***	***1.7***	***0.8***	***0.0***	***1.3***	
Trisomy 21 (Down syndrome)	164	97	47	18	0	373	
	9.8	***8.1***	***9.0***	***6.9***	***0.0***	***10.2***	
Turner syndrome†	5	3	2	1	0	12	
	0.6	***0.5***	***0.8***	***0.8***	***0.0***	***0.7***	
Ventricular septal defect	26	28	3	3	0	72	1
	1.6	***2.3***	***0.6***	***1.1***	***0.0***	***2.0***	
Total live births	**166571**	**120483**	**51948**	**26252**	**779**	**366789**	
Male live births	**85188**	**61119**	**26471**	**13598**	**388**	**187175**	
Female live births	**81383**	**59364**	**25477**	**12654**	**391**	**179614**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

Maryland

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	15	3	24	
	0.5	***0.4***	***0.7***	
Trisomy 13	7	13	20	
	0.2	***1.9***	***0.5***	
Trisomy 18	26	22	49	
	0.9	***3.3***	***1.3***	
Trisomy 21 (Down syndrome)	169	186	373	
	5.6	***27.5***	***10.2***	
Total live births	**299139**	**67650**	**366789**	

**Total includes unknown maternal age

Notes
1.Data for this condition include probable cases.

General comments
-Fetal deaths defined as gestational age greater than 20 weeks.
-Terminations defined as gestational age less than or equal to 20 weeks.

Massachusetts

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	31	4	12	3	0	59	
	1.3	***1.2***	***2.0***	***1.0***	***0.0***	***1.6***	
Anophthalmia/microphthalmia	28	4	13	3	0	48	
	1.2	***1.2***	***2.2***	***1.0***	***0.0***	***1.3***	
Anotia/microtia	42	4	18	9	0	75	
	1.8	***1.2***	***3.0***	***2.9***	***0.0***	***2.1***	
Aortic valve stenosis	36	3	5	2	0	46	
	1.5	***0.9***	***0.8***	***0.7***	***0.0***	***1.3***	
Atrial septal defect	524	99	129	64	1	827	
	22.4	***28.6***	***21.6***	***21.0***	***9.6***	***22.6***	
Atrioventricular septal defect (Endocardial cushion defect)	133	29	45	13	0	226	
	5.7	***8.4***	***7.5***	***4.3***	***0.0***	***6.2***	
Biliary atresia	8	2	6	4	0	20	
	0.3	***0.6***	***1.0***	***1.3***	***0.0***	***0.5***	
Bladder exstrophy	8	0	1	0	0	9	
	0.3	***0.0***	***0.2***	***0.0***	***0.0***	***0.2***	
Choanal atresia	20	0	5	0	0	26	
	0.9	***0.0***	***0.8***	***0.0***	***0.0***	***0.7***	
Cleft lip alone	88	9	13	15	0	127	
	3.8	***2.6***	***2.2***	***4.9***	***0.0***	***3.5***	
Cleft lip with cleft palate	125	8	35	12	0	185	
	5.3	***2.3***	***5.9***	***3.9***	***0.0***	***5.1***	
Cleft palate alone	134	19	31	16	0	203	1
	5.7	***5.5***	***5.2***	***5.2***	***0.0***	***5.6***	
Cloacal exstrophy	8	1	3	0	0	12	
	0.3	***0.3***	***0.5***	***0.0***	***0.0***	***0.3***	
Clubfoot	348	45	77	29	3	521	2
	14.9	***13.0***	***12.9***	***9.5***	***28.8***	***14.3***	
Coarctation of the aorta	112	19	28	6	0	166	
	4.8	***5.5***	***4.7***	***2.0***	***0.0***	***4.5***	
Common truncus (truncus arteriosus)	8	1	2	1	1	14	
	0.3	***0.3***	***0.3***	***0.3***	***9.6***	***0.4***	
Congenital cataract	55	8	24	2	0	89	
	2.4	***2.3***	***4.0***	***0.7***	***0.0***	***2.4***	
Congenital posterior urethral valves	14	10	9	7	0	44	
	0.6	***2.9***	***1.5***	***2.3***	***0.0***	***1.2***	
Craniosynostosis	145	7	26	7	1	189	
	6.2	***2.0***	***4.4***	***2.3***	***9.6***	***5.2***	
Deletion 22q11.2	29	5	11	7	0	53	
	1.2	***1.4***	***1.8***	***2.3***	***0.0***	***1.5***	
Diaphragmatic hernia	71	6	17	8	0	105	
	3.0	***1.7***	***2.8***	***2.6***	***0.0***	***2.9***	
Double outlet right ventricle	31	3	12	7	0	53	
	1.3	***0.9***	***2.0***	***2.3***	***0.0***	***1.5***	
Ebstein anomaly	9	1	5	0	0	16	
	0.4	***0.3***	***0.8***	***0.0***	***0.0***	***0.4***	
Encephalocele	15	3	9	4	0	34	
	0.6	***0.9***	***1.5***	***1.3***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	79	9	19	2	0	109	
	3.4	***2.6***	***3.2***	***0.7***	***0.0***	***3.0***	
Gastroschisis	69	15	29	7	0	125	
	3.0	***4.3***	***4.9***	***2.3***	***0.0***	***3.4***	
Holoprosencephaly	26	3	13	3	0	48	
	1.1	***0.9***	***2.2***	***1.0***	***0.0***	***1.3***	
Hypoplastic left heart syndrome	43	8	14	5	0	73	
	1.8	***2.3***	***2.3***	***1.6***	***0.0***	***2.0***	
Hypospadias*	338	50	43	26	1	468	3
	28.3	***28.2***	***14.0***	***16.5***	***19.8***	***25.0***	
Interrupted aortic arch	11	3	2	0	0	16	
	0.5	***0.9***	***0.3***	***0.0***	***0.0***	***0.4***	

Massachusetts

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	113	19	26	9	0	172	
	4.8	***5.5***	***4.4***	***2.9***	***0.0***	***4.7***	
Omphalocele	66	7	23	2	0	101	
	2.8	***2.0***	***3.8***	***0.7***	***0.0***	***2.8***	
Pulmonary valve atresia and stenosis	191	50	45	19	1	311	
	8.2	***14.4***	***7.5***	***6.2***	***9.6***	***8.5***	
Pulmonary valve atresia	13	3	4	2	0	22	
	0.6	***0.9***	***0.7***	***0.7***	***0.0***	***0.6***	
Rectal and large intestinal atresia/stenosis	92	13	25	12	0	148	
	3.9	***3.8***	***4.2***	***3.9***	***0.0***	***4.1***	
Renal agenesis/hypoplasia	13	2	3	1	0	23	4
	0.6	***0.6***	***0.5***	***0.3***	***0.0***	***0.6***	
Single ventricle	10	2	0	3	0	15	
	0.4	***0.6***	***0.0***	***1.0***	***0.0***	***0.4***	
Small intestinal atresia/stenosis	65	10	22	7	0	106	
	2.8	***2.9***	***3.7***	***2.3***	***0.0***	***2.9***	
Spina bifida without anencephalus	80	7	23	5	0	122	
	3.4	***2.0***	***3.8***	***1.6***	***0.0***	***3.3***	
Tetralogy of Fallot	109	15	27	14	1	171	5
	4.7	***4.3***	***4.5***	***4.6***	***9.6***	***4.7***	
Total anomalous pulmonary venous connection	13	3	8	10	0	34	
	0.6	***0.9***	***1.3***	***3.3***	***0.0***	***0.9***	
Transposition of the great arteries (TGA)	66	11	18	9	0	107	
	2.8	***3.2***	***3.0***	***2.9***	***0.0***	***2.9***	
Dextro-transposition of great arteries (d-TGA)	54	10	17	9	0	93	
	2.3	***2.9***	***2.8***	***2.9***	***0.0***	***2.5***	
Tricuspid valve atresia and stenosis	13	3	5	1	0	22	
	0.6	***0.9***	***0.8***	***0.3***	***0.0***	***0.6***	
Tricuspid valve atresia	8	1	4	1	0	14	
	0.3	***0.3***	***0.7***	***0.3***	***0.0***	***0.4***	
Trisomy 13	46	3	8	5	0	69	
	2.0	***0.9***	***1.3***	***1.6***	***0.0***	***1.9***	
Trisomy 18	94	16	30	14	0	171	
	4.0	***4.6***	***5.0***	***4.6***	***0.0***	***4.7***	
Trisomy 21 (Down syndrome)	450	65	115	50	0	721	
	19.2	***18.8***	***19.2***	***16.4***	***0.0***	***19.7***	
Turner syndrome†	65	6	10	5	1	106	
	5.7	***3.6***	***3.4***	***3.4***	***18.7***	***5.9***	
Ventricular septal defect	517	80	139	70	1	815	6
	22.1	***23.1***	***23.3***	***22.9***	***9.6***	***22.3***	
Total live births §	**233822**	**34653**	**59764**	**30541**	**1042**	**365243**	
Male live births	**119629**	**17758**	**30606**	**15771**	**506**	**187029**	
Female live births	**114190**	**16893**	**29156**	**14770**	**536**	**178206**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births. Excludes male phenotype.
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Massachusetts

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	118	6	125	
	4.2	***0.7***	***3.4***	
Trisomy 13	29	40	69	
	1.0	***4.9***	***1.9***	
Trisomy 18	59	108	171	
	2.1	***13.1***	***4.7***	
Trisomy 21 (Down syndrome)	300	419	721	
	10.6	***50.9***	***19.7***	
Total live births	**282845**	**82382**	**365243**	

**Total includes unknown maternal age

Notes
1.Data for this condition exclude isolated submucous cleft palate.
2.Data for this condition is limited to those who require casting or other treatment if the case is live birth.
3.Data for this condition exclude 1st degree and not otherwise specified.
4.Data for this condition exclude isolated unilateral renal agenesis/hypoplasia.
5.Data for this condition include pulmonary atresia with ventricular septal defect.
6.Data for this condition exclude isolated muscular ventricular septal defect.

General comments
-Coding system is modified CDC/BPA, but with different modified BPA codes for congenital cataract, diaphragmatic hernia, and double outlet right ventricle.
-Excludes probable and possible cases.
-For live births, race/ethnicity from vital records; new birth certificate in 2011--multiple categories allowed.
-For stillbirths without vital record info and for unspecified non-livebirths, race/ethnicity from medical record.
-Pregnancy outcomes include live births, stillbirths, and starting in 2011, unspecified non-live births.
-Stillbirths defined as fetal deaths >= 20 weeks or >=350 grams.
-Unspecified non-live births include elective terminations and early losses <20 weeks or <350 grams.

Michigan

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	49	5	4	2	0	61	
	1.2	***0.5***	***1.0***	***1.1***	***0.0***	***1.1***	
Anophthalmia/microphthalmia	45	16	3	0	0	64	
	1.1	***1.5***	***0.7***	***0.0***	***0.0***	***1.1***	
Anotia/microtia	37	10	14	4	0	85	
	0.9	***0.9***	***3.5***	***2.1***	***0.0***	***1.5***	
Aortic valve stenosis	89	10	7	5	0	115	
	2.3	***0.9***	***1.7***	***2.6***	***0.0***	***2.0***	
Atrial septal defect	3290	1489	271	174	32	5332	
	83.5	***141.1***	***67.6***	***91.5***	***137.2***	***93.1***	
Atrioventricular septal defect (Endocardial cushion defect)	215	46	19	7	0	290	
	5.5	***4.4***	***4.7***	***3.7***	***0.0***	***5.1***	
Biliary atresia	39	21	9	1	0	72	
	1.0	***2.0***	***2.2***	***0.5***	***0.0***	***1.3***	
Bladder exstrophy	11	0	0	0	0	11	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	70	29	3	4	1	110	
	1.8	***2.7***	***0.7***	***2.1***	***4.3***	***1.9***	
Cleft lip alone	194	25	11	6	0	240	
	4.9	***2.4***	***2.7***	***3.2***	***0.0***	***4.2***	
Cleft lip with cleft palate	209	39	20	10	2	287	
	5.3	***3.7***	***5.0***	***5.3***	***8.6***	***5.0***	
Cleft palate alone	215	40	20	8	1	290	
	5.5	***3.8***	***5.0***	***4.2***	***4.3***	***5.1***	
Cloacal exstrophy	173	59	23	6	2	265	
	4.4	***5.6***	***5.7***	***3.2***	***8.6***	***4.6***	
Clubfoot	493	153	29	32	5	720	
	12.5	***14.5***	***7.2***	***16.8***	***21.4***	***12.6***	
Coarctation of the aorta	873	447	82	47	4	1479	
	22.1	***42.3***	***20.4***	***24.7***	***17.1***	***25.8***	
Common truncus (truncus arteriosus)	49	20	0	3	1	73	
	1.2	***1.9***	***0.0***	***1.6***	***4.3***	***1.3***	
Congenital cataract	72	16	5	4	0	99	
	1.8	***1.5***	***1.2***	***2.1***	***0.0***	***1.7***	
Congenital posterior urethral valves	50	22	1	2	0	75	
	1.3	***2.1***	***0.2***	***1.1***	***0.0***	***1.3***	
Deletion 22q11.2	17	5	1	1	0	24	
	0.4	***0.5***	***0.2***	***0.5***	***0.0***	***0.4***	
Diaphragmatic hernia	116	33	16	11	1	181	
	2.9	***3.1***	***4.0***	***5.8***	***4.3***	***3.2***	
Double outlet right ventricle	96	25	11	9	0	141	
	2.4	***2.4***	***2.7***	***4.7***	***0.0***	***2.5***	
Ebstein anomaly	35	8	2	0	0	45	
	0.9	***0.8***	***0.5***	***0.0***	***0.0***	***0.8***	
Encephalocele	34	9	2	1	0	47	
	0.9	***0.9***	***0.5***	***0.5***	***0.0***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	91	13	5	4	0	115	
	2.3	***1.2***	***1.2***	***2.1***	***0.0***	***2.0***	
Gastroschisis	155	45	11	2	0	218	
	3.9	***4.3***	***2.7***	***1.1***	***0.0***	***3.8***	
Holoprosencephaly	213	92	18	11	1	347	
	5.4	***8.7***	***4.5***	***5.8***	***4.3***	***6.1***	
Hypoplastic left heart syndrome	162	56	14	5	1	242	
	4.1	***5.3***	***3.5***	***2.6***	***4.3***	***4.2***	
Hypospadias*	1285	278	69	57	6	1731	
	63.5	***51.7***	***33.8***	***57.9***	***50.0***	***59.0***	
Interrupted aortic arch	37	9	2	4	0	52	
	0.9	***0.9***	***0.5***	***2.1***	***0.0***	***0.9***	
Limb deficiencies (reduction defects)	148	54	12	8	1	225	
	3.8	***5.1***	***3.0***	***4.2***	***4.3***	***3.9***	

Michigan

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	59	23	4	1	0	88	
	1.5	***2.2***	***1.0***	***0.5***	***0.0***	***1.5***	
Pulmonary valve atresia and stenosis	317	146	31	18	2	525	
	8.0	***13.8***	***7.7***	***9.5***	***8.6***	***9.2***	
Pulmonary valve atresia	79	39	10	5	0	138	
	2.0	***3.7***	***2.5***	***2.6***	***0.0***	***2.4***	
Rectal and large intestinal atresia/stenosis	176	60	13	9	2	263	
	4.5	***5.7***	***3.2***	***4.7***	***8.6***	***4.6***	
Renal agenesis/hypoplasia	186	61	17	11	3	282	
	4.7	***5.8***	***4.2***	***5.8***	***12.9***	***4.9***	
Single ventricle	46	30	12	2	0	93	
	1.2	***2.8***	***3.0***	***1.1***	***0.0***	***1.6***	
Small intestinal atresia/stenosis	158	52	12	3	0	230	
	4.0	***4.9***	***3.0***	***1.6***	***0.0***	***4.0***	
Spina bifida without anencephalus	152	28	10	9	0	203	
	3.9	***2.7***	***2.5***	***4.7***	***0.0***	***3.5***	
Tetralogy of Fallot	202	69	20	11	1	305	
	5.1	***6.5***	***5.0***	***5.8***	***4.3***	***5.3***	
Total anomalous pulmonary venous connection	48	15	7	2	1	75	
	1.2	***1.4***	***1.7***	***1.1***	***4.3***	***1.3***	
Transposition of the great arteries (TGA)	203	51	18	18	1	293	
	5.2	***4.8***	***4.5***	***9.5***	***4.3***	***5.1***	
Dextro-transposition of great arteries (d-TGA)	119	36	12	9	1	179	
	3.0	***3.4***	***3.0***	***4.7***	***4.3***	***3.1***	
Tricuspid valve atresia and stenosis	50	13	6	1	0	72	
	1.3	***1.2***	***1.5***	***0.5***	***0.0***	***1.3***	
Trisomy 13	17	13	2	2	0	35	
	0.4	***1.2***	***0.5***	***1.1***	***0.0***	***0.6***	
Trisomy 18	43	18	8	3	0	75	
	1.1	***1.7***	***2.0***	***1.6***	***0.0***	***1.3***	
Trisomy 21 (Down syndrome)	505	128	36	27	0	712	
	12.8	***12.1***	***9.0***	***14.2***	***0.0***	***12.4***	
Turner syndrome†	32	3	4	2	0	42	
	1.7	***0.6***	***2.0***	***2.2***	***0.0***	***1.5***	
Ventricular septal defect	1475	426	147	94	11	2183	1
	37.4	***40.4***	***36.7***	***49.4***	***47.1***	***38.1***	
Total live births §	**394150**	**105554**	**40106**	**19018**	**2333**	**572776**	
Male live births	**202262**	**53739**	**20418**	**9839**	**1200**	**293457**	
Female live births	**191882**	**51810**	**19687**	**9178**	**1133**	**279304**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Michigan

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	216	2	218	
	4.3	***0.3***	***3.8***	
Trisomy 13	25	10	35	
	0.5	***1.4***	***0.6***	
Trisomy 18	40	34	75	
	0.8	***4.6***	***1.3***	
Trisomy 21 (Down syndrome)	411	301	712	
	8.2	***40.9***	***12.4***	
Total live births	**499068**	**73655**	**572776**	

**Total includes unknown maternal age

Notes
1.Data for this condition include probable cases.

General comments
-Data for conditions include live births only.

Minnesota

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	2	2	6	5	0	15	
	0.3	***0.9***	***5.1***	***3.0***	***0.0***	***1.3***	
Anophthalmia/microphthalmia	5	4	2	1	0	12	
	0.8	***1.7***	***1.7***	***0.6***	***0.0***	***1.0***	
Anotia/microtia	9	4	7	7	2	30	
	1.4	***1.7***	***6.0***	***4.2***	***14.7***	***2.5***	
Aortic valve stenosis	14	4	1	1	0	20	
	2.2	***1.7***	***0.9***	***0.6***	***0.0***	***1.7***	
Atrial septal defect	98	53	20	27	3	204	
	15.5	***22.7***	***17.0***	***16.1***	***22.1***	***17.2***	
Atrioventricular septal defect (Endocardial cushion defect)	33	15	10	7	1	68	1
	5.2	***6.4***	***8.5***	***4.2***	***7.4***	***5.7***	
Biliary atresia	4	3	1	0	0	8	
	0.6	***1.3***	***0.9***	***0.0***	***0.0***	***0.7***	
Bladder exstrophy	3	0	0	0	0	3	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Choanal atresia	9	4	2	0	0	15	
	1.4	***1.7***	***1.7***	***0.0***	***0.0***	***1.3***	
Cleft lip alone	17	5	3	8	0	36	
	2.7	***2.1***	***2.6***	***4.8***	***0.0***	***3.0***	
Cleft lip with cleft palate	34	14	5	10	2	68	
	5.4	***6.0***	***4.3***	***6.0***	***14.7***	***5.7***	
Cleft palate alone	50	10	3	6	0	69	
	7.9	***4.3***	***2.6***	***3.6***	***0.0***	***5.8***	
Coarctation of the aorta	35	10	5	3	1	57	
	5.5	***4.3***	***4.3***	***1.8***	***7.4***	***4.8***	
Common truncus (truncus arteriosus)	2	0	0	1	0	4	
	0.3	***0.0***	***0.0***	***0.6***	***0.0***	***0.3***	
Congenital cataract	10	4	0	0	0	14	
	1.6	***1.7***	***0.0***	***0.0***	***0.0***	***1.2***	
Congenital posterior urethral valves	6	8	0	2	0	16	
	0.9	***3.4***	***0.0***	***1.2***	***0.0***	***1.4***	
Diaphragmatic hernia	19	5	4	5	0	33	
	3.0	***2.1***	***3.4***	***3.0***	***0.0***	***2.8***	
Double outlet right ventricle	9	6	3	1	1	20	
	1.4	***2.6***	***2.6***	***0.6***	***7.4***	***1.7***	
Ebstein anomaly	3	3	1	1	0	8	
	0.5	***1.3***	***0.9***	***0.6***	***0.0***	***0.7***	
Encephalocele	4	1	1	3	1	10	
	0.6	***0.4***	***0.9***	***1.8***	***7.4***	***0.8***	
Esophageal atresia/tracheoesophageal fistula	17	7	3	5	0	32	
	2.7	***3.0***	***2.6***	***3.0***	***0.0***	***2.7***	
Gastroschisis	16	3	6	10	1	37	
	2.5	***1.3***	***5.1***	***6.0***	***7.4***	***3.1***	
Hypoplastic left heart syndrome	13	5	3	1	0	23	
	2.1	***2.1***	***2.6***	***0.6***	***0.0***	***1.9***	
Hypospadias*	245	81	18	17	3	376	
	75.5	***67.8***	***30.4***	***19.7***	***44.1***	***62.0***	
Limb deficiencies (reduction defects)	24	10	2	6	1	43	2
	3.8	***4.3***	***1.7***	***3.6***	***7.4***	***3.6***	
Omphalocele	13	3	1	1	0	18	
	2.1	***1.3***	***0.9***	***0.6***	***0.0***	***1.5***	
Pulmonary valve atresia and stenosis	55	27	13	17	5	117	
	8.7	***11.6***	***11.1***	***10.2***	***36.8***	***9.9***	
Pulmonary valve atresia	4	5	0	1	1	11	
	0.6	***2.1***	***0.0***	***0.6***	***7.4***	***0.9***	
Rectal and large intestinal atresia/stenosis	24	8	0	9	0	41	
	3.8	***3.4***	***0.0***	***5.4***	***0.0***	***3.5***	
Renal agenesis/hypoplasia	32	11	5	7	0	56	
	5.1	***4.7***	***4.3***	***4.2***	***0.0***	***4.7***	

Minnesota

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Single ventricle	3	1	0	1	0	5	
	0.5	***0.4***	***0.0***	***0.6***	***0.0***	***0.4***	
Spina bifida without anencephalus	15	6	3	1	1	29	
	2.4	***2.6***	***2.6***	***0.6***	***7.4***	***2.5***	
Tetralogy of Fallot	23	2	3	6	0	36	3
	3.6	***0.9***	***2.6***	***3.6***	***0.0***	***3.0***	
Transposition of the great arteries (TGA)	17	8	4	3	1	33	
	2.7	***3.4***	***3.4***	***1.8***	***7.4***	***2.8***	
Dextro-transposition of great arteries (d-TGA)	17	7	4	2	1	31	
	2.7	***3.0***	***3.4***	***1.2***	***7.4***	***2.6***	
Tricuspid valve atresia	3	5	1	0	0	9	
	0.5	***2.1***	***0.9***	***0.0***	***0.0***	***0.8***	
Trisomy 13	2	6	3	0	0	11	
	0.3	***2.6***	***2.6***	***0.0***	***0.0***	***0.9***	
Trisomy 18	11	11	1	6	0	29	
	1.7	***4.7***	***0.9***	***3.6***	***0.0***	***2.5***	
Trisomy 21 (Down syndrome)	115	45	28	15	3	207	
	18.2	***19.3***	***23.8***	***9.0***	***22.1***	***17.5***	
Ventricular septal defect	319	127	62	60	13	593	4
	50.5	***54.4***	***52.8***	***35.8***	***95.7***	***50.1***	
Total live births	**63194**	**23347**	**11752**	**16742**	**1358**	**118308**	
Male live births	**32458**	**11940**	**5914**	**8628**	**681**	**60630**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

Minnesota

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	37	0	37	
	3.8	***0.0***	***3.1***	
Trisomy 13	6	5	11	
	0.6	***2.4***	***0.9***	
Trisomy 18	15	14	29	
	1.5	***6.7***	***2.5***	
Trisomy 21 (Down syndrome)	111	96	207	
	11.4	***45.6***	***17.5***	
Total live births	**97257**	**21047**	**118308**	

**Total includes unknown maternal age

Notes
1.Data for this condition exclude inlet ventricular septal defect.
2.Data for this condition exclude other specified reduction defect of lower limb, transverse reduction defect of lower limb not otherwise specified, unspecified reduction defect of lower limb, and reduction defects of unspecified limb.
3.Data for this condition exclude pulmonary artery atresia with septal defect.
4.Data for this condition include inlet ventricular septal defect.

General comments
-Data are for Hennepin and Ramsey Counties only.
-Excludes probable and possible cases.

Mississippi

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	1	5	0	0	0	6	
	0.1	***0.6***	***0.0***	***0.0***	***0.0***	***0.3***	
Anophthalmia/microphthalmia	6	5	0	0	0	11	
	0.6	***0.6***	***0.0***	***0.0***	***0.0***	***0.6***	
Anotia/microtia	14	14	2	1	2	34	
	1.4	***1.6***	***3.0***	***4.2***	***14.7***	***1.7***	
Aortic valve stenosis	19	4	1	0	0	24	
	1.9	***0.5***	***1.5***	***0.0***	***0.0***	***1.2***	
Atrial septal defect	1341	1566	45	23	64	3107	
	131.3	***180.3***	***66.9***	***96.0***	***469.2***	***155.5***	
Atrioventricular septal defect (Endocardial cushion defect)	51	50	3	3	0	112	
	5.0	***5.8***	***4.5***	***12.5***	***0.0***	***5.6***	
Biliary atresia	6	9	1	0	0	17	
	0.6	***1.0***	***1.5***	***0.0***	***0.0***	***0.9***	
Bladder exstrophy	3	1	0	0	0	5	
	0.3	***0.1***	***0.0***	***0.0***	***0.0***	***0.3***	
Choanal atresia	3	2	0	0	0	5	
	0.3	***0.2***	***0.0***	***0.0***	***0.0***	***0.3***	
Cleft lip alone	25	11	1	1	1	43	
	2.4	***1.3***	***1.5***	***4.2***	***7.3***	***2.2***	
Cleft lip with cleft palate	55	45	2	4	1	119	
	5.4	***5.2***	***3.0***	***16.7***	***7.3***	***6.0***	
Cleft palate alone	33	19	3	2	0	61	
	3.2	***2.2***	***4.5***	***8.3***	***0.0***	***3.1***	
Cloacal exstrophy	1	2	1	0	0	4	
	0.1	***0.2***	***1.5***	***0.0***	***0.0***	***0.2***	
Clubfoot	2	0	1	0	0	3	
	0.2	***0.0***	***1.5***	***0.0***	***0.0***	***0.2***	
Coarctation of the aorta	36	36	1	0	0	73	
	3.5	***4.1***	***1.5***	***0.0***	***0.0***	***3.7***	
Common truncus (truncus arteriosus)	10	5	1	0	0	16	
	1.0	***0.6***	***1.5***	***0.0***	***0.0***	***0.8***	
Congenital cataract	2	9	0	0	0	11	
	0.2	***1.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Congenital posterior urethral valves	18	24	1	0	0	45	
	1.8	***2.8***	***1.5***	***0.0***	***0.0***	***2.3***	
Deletion 22q11.2	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Diaphragmatic hernia	23	18	2	1	0	50	
	2.3	***2.1***	***3.0***	***4.2***	***0.0***	***2.5***	
Double outlet right ventricle	19	24	2	2	0	48	
	1.9	***2.8***	***3.0***	***8.3***	***0.0***	***2.4***	
Ebstein anomaly	10	5	0	0	0	15	
	1.0	***0.6***	***0.0***	***0.0***	***0.0***	***0.8***	
Encephalocele	2	2	1	0	1	6	
	0.2	***0.2***	***1.5***	***0.0***	***7.3***	***0.3***	
Esophageal atresia/tracheoesophageal fistula	28	17	2	0	2	50	
	2.7	***2.0***	***3.0***	***0.0***	***14.7***	***2.5***	
Holoprosencephaly	2	2	0	0	0	4	
	0.2	***0.2***	***0.0***	***0.0***	***0.0***	***0.2***	
Hypoplastic left heart syndrome	44	23	0	0	0	68	
	4.3	***2.6***	***0.0***	***0.0***	***0.0***	***3.4***	
Hypospadias*	358	404	8	4	1	789	
	68.2	***92.8***	***23.8***	***32.5***	***15.1***	***77.7***	
Interrupted aortic arch	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Limb deficiencies (reduction defects)	37	36	1	1	1	76	
	3.6	***4.1***	***1.5***	***4.2***	***7.3***	***3.8***	
Pulmonary valve atresia and stenosis	125	131	3	3	1	271	
	12.2	***15.1***	***4.5***	***12.5***	***7.3***	***13.6***	

Mississippi

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Rectal and large intestinal atresia/stenosis	29	33	2	2	1	68	
	2.8	***3.8***	***3.0***	***8.3***	***7.3***	***3.4***	
Renal agenesis/hypoplasia	12	14	1	1	1	29	
	1.2	***1.6***	***1.5***	***4.2***	***7.3***	***1.5***	
Single ventricle	0	1	0	0	0	1	
	0.0	***0.1***	***0.0***	***0.0***	***0.0***	***0.1***	
Small intestinal atresia/stenosis	4	4	0	0	0	8	
	0.4	***0.5***	***0.0***	***0.0***	***0.0***	***0.4***	
Spina bifida without anencephalus	31	24	1	1	0	59	
	3.0	***2.8***	***1.5***	***4.2***	***0.0***	***3.0***	
Tetralogy of Fallot	61	58	2	1	0	124	
	6.0	***6.7***	***3.0***	***4.2***	***0.0***	***6.2***	
Total anomalous pulmonary venous connection	2	1	0	1	0	4	
	0.2	***0.1***	***0.0***	***4.2***	***0.0***	***0.2***	
Transposition of the great arteries (TGA)	23	17	0	3	1	44	
	2.3	***2.0***	***0.0***	***12.5***	***7.3***	***2.2***	
Tricuspid valve atresia and stenosis	7	17	0	2	0	27	
	0.7	***2.0***	***0.0***	***8.3***	***0.0***	***1.4***	
Trisomy 13	4	6	0	1	0	11	
	0.4	***0.7***	***0.0***	***4.2***	***0.0***	***0.6***	
Trisomy 18	16	7	2	0	1	26	
	1.6	***0.8***	***3.0***	***0.0***	***7.3***	***1.3***	
Trisomy 21 (Down syndrome)	98	78	6	1	3	191	
	9.6	***9.0***	***8.9***	***4.2***	***22.0***	***9.6***	
Turner syndrome†	1	0	0	0	0	1	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Ventricular septal defect	575	527	34	13	17	1190	1
	56.3	***60.7***	***50.6***	***54.3***	***124.6***	***59.5***	
Total live births	**102170**	**86879**	**6725**	**2396**	**1364**	**199847**	
Male live births	**52519**	**43553**	**3362**	**1231**	**663**	**101497**	
Female live births	**49651**	**43326**	**3363**	**1165**	**701**	**98350**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

Mississippi

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Trisomy 13	11	0	11	
	0.6	***0.0***	***0.6***	
Trisomy 18	16	10	26	
	0.9	***6.4***	***1.3***	
Trisomy 21 (Down syndrome)	116	75	191	
	6.3	***48.0***	***9.6***	
Total live births	**184215**	**15618**	**199847**	

**Total includes unknown maternal age

Notes
1.Data for this condition does not include probable cases.

Missouri

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	37	5	7	1	0	51	
	1.3	***0.9***	***3.4***	***1.1***	***0.0***	***1.3***	
Anophthalmia/microphthalmia	29	4	2	1	0	36	
	1.0	***0.7***	***1.0***	***1.1***	***0.0***	***0.9***	
Anotia/microtia	13	5	5	3	0	26	
	0.5	***0.9***	***2.4***	***3.3***	***0.0***	***0.7***	
Aortic valve stenosis	50	1	3	0	0	54	
	1.7	***0.2***	***1.4***	***0.0***	***0.0***	***1.4***	
Atrial septal defect	3716	1012	256	94	19	5233	
	129.5	***182.9***	***123.6***	***102.4***	***192.3***	***136.9***	
Atrioventricular septal defect (Endocardial cushion defect)	129	24	6	2	0	163	
	4.5	***4.3***	***2.9***	***2.2***	***0.0***	***4.3***	
Biliary atresia	25	8	1	0	0	35	
	0.9	***1.4***	***0.5***	***0.0***	***0.0***	***0.9***	
Bladder exstrophy	14	1	0	0	0	15	
	0.5	***0.2***	***0.0***	***0.0***	***0.0***	***0.4***	
Choanal atresia	64	8	3	1	0	77	
	2.2	***1.4***	***1.4***	***1.1***	***0.0***	***2.0***	
Cleft lip alone	182	20	11	4	2	226	
	6.3	***3.6***	***5.3***	***4.4***	***20.2***	***5.9***	
Cleft lip with cleft palate	206	32	12	2	2	268	
	7.2	***5.8***	***5.8***	***2.2***	***20.2***	***7.0***	
Cleft palate alone	199	18	14	4	0	236	
	6.9	***3.3***	***6.8***	***4.4***	***0.0***	***6.2***	
Cloacal exstrophy	199	69	11	7	0	294	
	6.9	***12.5***	***5.3***	***7.6***	***0.0***	***7.7***	
Clubfoot	504	92	25	15	2	654	
	17.6	***16.6***	***12.1***	***16.3***	***20.2***	***17.1***	
Coarctation of the aorta	194	25	13	3	0	240	
	6.8	***4.5***	***6.3***	***3.3***	***0.0***	***6.3***	
Common truncus (truncus arteriosus)	16	3	3	0	0	23	
	0.6	***0.5***	***1.4***	***0.0***	***0.0***	***0.6***	
Congenital cataract	61	12	4	2	2	83	
	2.1	***2.2***	***1.9***	***2.2***	***20.2***	***2.2***	
Congenital posterior urethral valves	43	15	4	0	0	65	
	1.5	***2.7***	***1.9***	***0.0***	***0.0***	***1.7***	
Deletion 22q11.2	25	2	1	1	0	29	
	0.9	***0.4***	***0.5***	***1.1***	***0.0***	***0.8***	
Diaphragmatic hernia	130	37	5	2	0	175	
	4.5	***6.7***	***2.4***	***2.2***	***0.0***	***4.6***	
Double outlet right ventricle	66	22	5	2	0	97	
	2.3	***4.0***	***2.4***	***2.2***	***0.0***	***2.5***	
Ebstein anomaly	24	1	4	2	0	33	
	0.8	***0.2***	***1.9***	***2.2***	***0.0***	***0.9***	
Encephalocele	27	12	3	1	0	44	
	0.9	***2.2***	***1.4***	***1.1***	***0.0***	***1.2***	
Esophageal atresia/tracheoesophageal fistula	99	15	2	2	1	123	
	3.4	***2.7***	***1.0***	***2.2***	***10.1***	***3.2***	
Gastroschisis	164	38	16	3	0	225	
	5.7	***6.9***	***7.7***	***3.3***	***0.0***	***5.9***	
Holoprosencephaly	170	34	15	3	1	230	
	5.9	***6.1***	***7.2***	***3.3***	***10.1***	***6.0***	
Hypoplastic left heart syndrome	92	16	3	0	0	111	
	3.2	***2.9***	***1.4***	***0.0***	***0.0***	***2.9***	
Hypospadias*	1390	290	52	38	6	1808	
	94.2	***102.6***	***49.5***	***79.6***	***121.5***	***92.1***	
Interrupted aortic arch	15	4	3	0	0	22	
	0.5	***0.7***	***1.4***	***0.0***	***0.0***	***0.6***	
Limb deficiencies (reduction defects)	126	28	9	2	0	169	
	4.4	***5.1***	***4.3***	***2.2***	***0.0***	***4.4***	

Missouri

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	74	18	8	1	0	104	
	2.6	***3.3***	***3.9***	***1.1***	***0.0***	***2.7***	
Pulmonary valve atresia and stenosis	292	75	23	4	1	403	
	10.2	***13.6***	***11.1***	***4.4***	***10.1***	***10.5***	
Pulmonary valve atresia	43	14	2	1	0	61	
	1.5	***2.5***	***1.0***	***1.1***	***0.0***	***1.6***	
Rectal and large intestinal atresia/stenosis	145	25	7	7	2	190	
	5.1	***4.5***	***3.4***	***7.6***	***20.2***	***5.0***	
Renal agenesis/hypoplasia	127	38	8	6	0	181	
	4.4	***6.9***	***3.9***	***6.5***	***0.0***	***4.7***	
Single ventricle	28	8	1	0	0	38	
	1.0	***1.4***	***0.5***	***0.0***	***0.0***	***1.0***	
Small intestinal atresia/stenosis	113	31	8	2	0	159	
	3.9	***5.6***	***3.9***	***2.2***	***0.0***	***4.2***	
Spina bifida without anencephalus	85	6	7	0	0	101	
	3.0	***1.1***	***3.4***	***0.0***	***0.0***	***2.6***	
Tetralogy of Fallot	130	33	13	3	2	183	
	4.5	***6.0***	***6.3***	***3.3***	***20.2***	***4.8***	
Total anomalous pulmonary venous connection	20	4	1	0	0	27	
	0.7	***0.7***	***0.5***	***0.0***	***0.0***	***0.7***	
Transposition of the great arteries (TGA)	123	13	6	3	0	146	
	4.3	***2.3***	***2.9***	***3.3***	***0.0***	***3.8***	
Dextro-transposition of great arteries (d-TGA)	113	10	4	2	0	130	
	3.9	***1.8***	***1.9***	***2.2***	***0.0***	***3.4***	
Tricuspid valve atresia and stenosis	35	10	1	1	0	47	
	1.2	***1.8***	***0.5***	***1.1***	***0.0***	***1.2***	
Trisomy 13	22	6	3	0	0	31	
	0.8	***1.1***	***1.4***	***0.0***	***0.0***	***0.8***	
Trisomy 18	40	11	7	0	0	58	
	1.4	***2.0***	***3.4***	***0.0***	***0.0***	***1.5***	
Trisomy 21 (Down syndrome)	382	64	46	11	4	519	
	13.3	***11.6***	***22.2***	***12.0***	***40.5***	***13.6***	
Turner syndrome†	23	2	0	0	0	26	
	1.6	***0.7***	***0.0***	***0.0***	***0.0***	***1.4***	
Ventricular septal defect	1359	281	116	35	3	1831	
	47.3	***50.8***	***56.0***	***38.1***	***30.4***	***47.9***	
Total live births §	**287030**	**55345**	**20709**	**9184**	**988**	**382280**	
Male live births	**147495**	**28276**	**10504**	**4774**	**494**	**196224**	
Female live births	**139531**	**27067**	**10204**	**4410**	**494**	**186049**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births. Excludes male phenotype.
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Missouri

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	220	5	225	
	6.4	***1.2***	***5.9***	
Trisomy 13	20	11	31	
	0.6	***2.7***	***0.8***	
Trisomy 18	36	22	58	
	1.1	***5.4***	***1.5***	
Trisomy 21 (Down syndrome)	300	219	519	
	8.8	***53.4***	***13.6***	
Total live births	**341198**	**41026**	**382280**	

**Total includes unknown maternal age

Nebraska

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	13	0	8	0	0	21	
	1.3	***0.0***	***4.1***	***0.0***	***0.0***	***1.6***	
Anophthalmia/microphthalmia	14	1	0	1	1	20	
	1.5	***1.1***	***0.0***	***2.8***	***5.1***	***1.5***	
Anotia/microtia	17	0	13	1	0	31	
	1.8	***0.0***	***6.7***	***2.8***	***0.0***	***2.4***	
Aortic valve stenosis	23	0	3	0	0	27	
	2.4	***0.0***	***1.5***	***0.0***	***0.0***	***2.1***	
Atrial septal defect	167	9	28	7	3	218	
	17.3	***10.3***	***14.4***	***19.8***	***15.4***	***16.7***	
Atrioventricular septal defect (Endocardial cushion defect)	23	1	4	2	0	32	
	2.4	***1.1***	***2.1***	***5.7***	***0.0***	***2.5***	
Biliary atresia	4	1	0	0	0	5	
	0.4	***1.1***	***0.0***	***0.0***	***0.0***	***0.4***	
Bladder exstrophy	6	1	0	0	0	7	
	0.6	***1.1***	***0.0***	***0.0***	***0.0***	***0.5***	
Choanal atresia	19	1	4	0	0	24	
	2.0	***1.1***	***2.1***	***0.0***	***0.0***	***1.8***	
Cleft lip alone	38	3	9	5	3	59	
	3.9	***3.4***	***4.6***	***14.1***	***15.4***	***4.5***	
Cleft lip with cleft palate	56	4	14	6	4	87	
	5.8	***4.6***	***7.2***	***17.0***	***20.6***	***6.7***	
Cleft palate alone	56	5	11	4	1	83	
	5.8	***5.7***	***5.7***	***11.3***	***5.1***	***6.4***	
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	160	14	31	5	3	216	
	16.6	***16.1***	***16.0***	***14.1***	***15.4***	***16.5***	
Coarctation of the aorta	87	0	13	3	0	107	
	9.0	***0.0***	***6.7***	***8.5***	***0.0***	***8.2***	
Common truncus (truncus arteriosus)	8	1	2	0	0	12	
	0.8	***1.1***	***1.0***	***0.0***	***0.0***	***0.9***	
Congenital cataract	22	0	4	3	0	30	
	2.3	***0.0***	***2.1***	***8.5***	***0.0***	***2.3***	
Congenital posterior urethral valves	5	1	0	0	0	6	
	0.5	***1.1***	***0.0***	***0.0***	***0.0***	***0.5***	
Craniosynostosis	21	0	3	0	0	24	
	2.2	***0.0***	***1.5***	***0.0***	***0.0***	***1.8***	
Deletion 22q11.2	2	1	0	0	0	4	
	0.2	***1.1***	***0.0***	***0.0***	***0.0***	***0.3***	
Diaphragmatic hernia	12	2	6	1	2	23	
	1.2	***2.3***	***3.1***	***2.8***	***10.3***	***1.8***	
Double outlet right ventricle	12	2	2	1	2	19	
	1.2	***2.3***	***1.0***	***2.8***	***10.3***	***1.5***	
Ebstein anomaly	6	0	2	0	1	10	
	0.6	***0.0***	***1.0***	***0.0***	***5.1***	***0.8***	
Encephalocele	9	0	1	1	1	12	
	0.9	***0.0***	***0.5***	***2.8***	***5.1***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	24	1	6	0	0	31	
	2.5	***1.1***	***3.1***	***0.0***	***0.0***	***2.4***	
Gastroschisis	48	3	11	2	5	72	
	5.0	***3.4***	***5.7***	***5.7***	***25.7***	***5.5***	
Holoprosencephaly	6	1	3	1	0	11	
	0.6	***1.1***	***1.5***	***2.8***	***0.0***	***0.8***	
Hypoplastic left heart syndrome	42	5	5	0	2	56	
	4.4	***5.7***	***2.6***	***0.0***	***10.3***	***4.3***	
Hypospadias*	428	33	46	3	1	529	
	86.7	***75.5***	***46.1***	***16.7***	***9.8***	***79.2***	
Interrupted aortic arch	11	0	2	0	0	13	
	1.1	***0.0***	***1.0***	***0.0***	***0.0***	***1.0***	

Nebraska

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	57	5	9	1	1	75	
	5.9	***5.7***	***4.6***	***2.8***	***5.1***	***5.7***	
Omphalocele	24	3	1	1	0	30	
	2.5	***3.4***	***0.5***	***2.8***	***0.0***	***2.3***	
Pulmonary valve atresia and stenosis	5337	490	924	158	55	7143	
	553.3	***563.0***	***475.6***	***446.5***	***282.8***	***546.9***	
Pulmonary valve atresia	17	2	7	0	2	28	
	1.8	***2.3***	***3.6***	***0.0***	***10.3***	***2.1***	
Rectal and large intestinal atresia/stenosis	49	5	10	4	0	71	
	5.1	***5.7***	***5.1***	***11.3***	***0.0***	***5.4***	
Renal agenesis/hypoplasia	71	6	14	1	1	95	
	7.4	***6.9***	***7.2***	***2.8***	***5.1***	***7.3***	
Single ventricle	28	3	2	0	1	35	
	2.9	***3.4***	***1.0***	***0.0***	***5.1***	***2.7***	
Small intestinal atresia/stenosis	22	5	7	2	0	36	
	2.3	***5.7***	***3.6***	***5.7***	***0.0***	***2.8***	
Spina bifida without anencephalus	55	3	12	0	1	73	
	5.7	***3.4***	***6.2***	***0.0***	***5.1***	***5.6***	
Tetralogy of Fallot	32	2	5	2	1	42	
	3.3	***2.3***	***2.6***	***5.7***	***5.1***	***3.2***	
Total anomalous pulmonary venous connection	7	1	7	0	0	16	
	0.7	***1.1***	***3.6***	***0.0***	***0.0***	***1.2***	
Transposition of the great arteries (TGA)	56	2	5	0	0	67	
	5.8	***2.3***	***2.6***	***0.0***	***0.0***	***5.1***	
Dextro-transposition of great arteries (d-TGA)	45	2	4	0	0	55	
	4.7	***2.3***	***2.1***	***0.0***	***0.0***	***4.2***	
Tricuspid valve atresia and stenosis	14	4	1	0	0	21	
	1.5	***4.6***	***0.5***	***0.0***	***0.0***	***1.6***	
Trisomy 13	12	3	6	0	0	21	
	1.2	***3.4***	***3.1***	***0.0***	***0.0***	***1.6***	
Trisomy 18	38	5	8	2	0	54	
	3.9	***5.7***	***4.1***	***5.7***	***0.0***	***4.1***	
Trisomy 21 (Down syndrome)	184	8	40	5	1	244	
	19.1	***9.2***	***20.6***	***14.1***	***5.1***	***18.7***	
Turner syndrome†	14	1	4	0	0	19	
	3.0	***2.3***	***4.2***	***0.0***	***0.0***	***3.0***	
Ventricular septal defect	441	23	98	12	4	606	
	45.7	***26.4***	***50.4***	***33.9***	***20.6***	***46.4***	
Total live births §	**96466**	**8703**	**19429**	**3539**	**1945**	**130602**	
Male live births	**49392**	**4373**	**9987**	**1792**	**1019**	**66822**	
Female live births	**47074**	**4330**	**9440**	**1747**	**926**	**63778**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Nebraska

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	68	4	72	
	5.9	***2.6***	***5.5***	
Trisomy 13	16	5	21	
	1.4	***3.3***	***1.6***	
Trisomy 18	30	24	54	
	2.6	***15.6***	***4.1***	
Trisomy 21 (Down syndrome)	145	100	245	
	12.6	***65.1***	***18.8***	
Total live births	**115230**	**15367**	**130602**	

**Total includes unknown maternal age

Nevada

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	2	1	2	0	0	5	
	0.3	***0.6***	***0.3***	***0.0***	***0.0***	***0.3***	
Anophthalmia/microphthalmia	6	4	11	2	0	23	
	0.8	***2.2***	***1.7***	***1.4***	***0.0***	***1.3***	
Anotia/microtia	5	0	4	1	0	10	
	0.7	***0.0***	***0.6***	***0.7***	***0.0***	***0.6***	
Aortic valve stenosis	12	0	9	1	0	23	
	1.6	***0.0***	***1.4***	***0.9***	***0.0***	***1.3***	
Atrial septal defect	1192	434	990	248	17	2967	
	158.6	***240.3***	***151.7***	***173.0***	***96.0***	***167.1***	
Atrioventricular septal defect (Endocardial cushion defect)	14	8	12	2	0	37	
	1.9	***4.4***	***1.8***	***1.4***	***0.0***	***2.1***	
Biliary atresia	6	0	2	1	0	10	
	0.8	***0.0***	***0.3***	***0.7***	***0.0***	***0.6***	
Bladder exstrophy	3	0	2	0	0	6	
	0.4	***0.0***	***0.3***	***0.0***	***0.0***	***0.3***	
Choanal atresia	8	1	6	0	0	17	
	1.1	***0.6***	***0.9***	***0.0***	***0.0***	***1.0***	
Cleft lip alone	25	4	12	6	0	47	
	3.3	***2.2***	***1.8***	***4.2***	***0.0***	***2.6***	
Cleft lip with cleft palate	43	16	57	2	0	121	
	5.7	***8.9***	***8.7***	***1.4***	***0.0***	***6.8***	
Cleft palate alone	40	7	25	3	1	78	
	5.3	***3.9***	***3.8***	***2.1***	***5.6***	***4.4***	
Cloacal exstrophy	22	6	14	4	0	50	
	2.9	***3.3***	***2.1***	***2.8***	***0.0***	***2.8***	
Clubfoot	88	16	78	11	1	202	
	11.7	***8.9***	***12.0***	***7.7***	***5.6***	***11.4***	
Coarctation of the aorta	48	10	43	6	0	110	
	6.4	***5.5***	***6.6***	***4.2***	***0.0***	***6.2***	
Common truncus (truncus arteriosus)	1	1	6	0	0	8	
	0.1	***0.6***	***0.9***	***0.0***	***0.0***	***0.5***	
Congenital cataract	3	3	4	1	0	11	
	0.5	***2.1***	***0.8***	***0.9***	***0.0***	***0.8***	
Congenital posterior urethral valves	5	0	2	1	0	8	
	0.7	***0.0***	***0.3***	***0.7***	***0.0***	***0.5***	
Craniosynostosis	70	13	35	5	0	133	
	9.3	***7.2***	***5.4***	***3.5***	***0.0***	***7.5***	
Deletion 22q11.2	1	0	0	0	0	1	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Diaphragmatic hernia	16	5	20	3	0	45	
	2.1	***2.8***	***3.1***	***2.1***	***0.0***	***2.5***	
Double outlet right ventricle	9	3	14	1	0	29	
	1.2	***1.7***	***2.1***	***0.7***	***0.0***	***1.6***	
Ebstein anomaly	4	0	3	0	0	7	
	0.7	***0.0***	***0.6***	***0.0***	***0.0***	***0.5***	
Encephalocele	7	1	1	2	0	12	
	0.9	***0.6***	***0.2***	***1.4***	***0.0***	***0.7***	
Esophageal atresia/tracheoesophageal fistula	17	3	17	1	0	38	
	2.3	***1.7***	***2.6***	***0.7***	***0.0***	***2.1***	
Holoprosencephaly	39	13	24	13	0	90	
	5.2	***7.2***	***3.7***	***9.1***	***0.0***	***5.1***	
Hypoplastic left heart syndrome	15	4	14	1	0	37	
	2.0	***2.2***	***2.1***	***0.7***	***0.0***	***2.1***	
Hypospadias*	175	37	78	23	1	327	
	45.3	***40.3***	***23.3***	***30.7***	***11.0***	***35.9***	
Interrupted aortic arch	6	2	7	1	0	16	
	0.8	***1.1***	***1.1***	***0.7***	***0.0***	***0.9***	
Limb deficiencies (reduction defects)	31	7	18	2	1	60	
	4.1	***3.9***	***2.8***	***1.4***	***5.6***	***3.4***	

Nevada

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	82	35	55	8	3	189	
	10.9	***19.4***	***8.4***	***5.6***	***16.9***	***10.6***	
Pulmonary valve atresia	10	1	11	0	0	23	
	1.3	***0.6***	***1.7***	***0.0***	***0.0***	***1.3***	
Rectal and large intestinal atresia/stenosis	27	2	28	4	0	63	
	3.6	***1.1***	***4.3***	***2.8***	***0.0***	***3.5***	
Renal agenesis/hypoplasia	28	6	27	6	3	73	
	3.7	***3.3***	***4.1***	***4.2***	***16.9***	***4.1***	
Single ventricle	5	3	1	0	0	9	
	0.7	***1.7***	***0.2***	***0.0***	***0.0***	***0.5***	
Small intestinal atresia/stenosis	31	8	23	4	1	67	
	4.1	***4.4***	***3.5***	***2.8***	***5.6***	***3.8***	
Spina bifida without anencephalus	17	8	12	3	0	43	
	2.3	***4.4***	***1.8***	***2.1***	***0.0***	***2.4***	
Tetralogy of Fallot	22	5	26	5	2	61	
	2.9	***2.8***	***4.0***	***3.5***	***11.3***	***3.4***	
Total anomalous pulmonary venous connection	6	0	3	1	0	11	
	0.8	***0.0***	***0.5***	***0.7***	***0.0***	***0.6***	
Transposition of the great arteries (TGA)	9	6	6	1	0	23	
	1.2	***3.3***	***0.9***	***0.7***	***0.0***	***1.3***	
Dextro-transposition of great arteries (d-TGA)	7	5	4	0	0	17	
	0.9	***2.8***	***0.6***	***0.0***	***0.0***	***1.0***	
Tricuspid valve atresia and stenosis	19	11	13	3	0	50	
	2.5	***6.1***	***2.0***	***2.1***	***0.0***	***2.8***	
Tricuspid valve atresia	1	0	1	1	0	3	
	0.7	***0.0***	***0.8***	***3.5***	***0.0***	***0.9***	
Trisomy 13	6	1	7	1	0	15	
	0.8	***0.6***	***1.1***	***0.7***	***0.0***	***0.8***	
Trisomy 18	8	1	10	0	0	23	
	1.1	***0.6***	***1.5***	***0.0***	***0.0***	***1.3***	
Trisomy 21 (Down syndrome)	77	19	121	16	2	244	
	10.2	***10.5***	***18.5***	***11.2***	***11.3***	***13.7***	
Turner syndrome†	4	2	5	0	0	11	
	1.1	***2.3***	***1.6***	***0.0***	***0.0***	***1.3***	
Ventricular septal defect	366	70	329	50	7	859	1
	48.7	***38.8***	***50.4***	***34.9***	***39.5***	***48.4***	
Total live births	**75172**	**18058**	**65253**	**14335**	**1771**	**177507**	
Male live births	**38645**	**9179**	**33415**	**7499**	**908**	**91160**	
Female live births	**36527**	**8879**	**31838**	**6836**	**863**	**86347**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

Nevada

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Trisomy 13	8	6	15	
	0.5	***2.3***	***0.8***	
Trisomy 18	13	5	23	
	0.9	***1.9***	***1.3***	
Trisomy 21 (Down syndrome)	111	95	244	
	7.3	***36.2***	***13.7***	
Total live births	**151026**	**26233**	**177507**	

**Total includes unknown maternal age

Notes
1.Data for this condition excluded if less than 2500 grams birth weight or less than 36 weeks gestation.

General comments
-Data for conditions include live births and resident births only.
-Data for this condition exclude probable/possible cases.

New Jersey
Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	3	0	2	1	0	6	
	0.1	***0.0***	***0.1***	***0.2***	***0.0***	***0.1***	
Anophthalmia/microphthalmia	15	7	10	3	1	41	
	0.6	***0.9***	***0.7***	***0.5***	***17.7***	***0.8***	
Anotia/microtia	41	8	71	9	0	130	
	1.8	***1.0***	***5.2***	***1.6***	***0.0***	***2.5***	
Aortic valve stenosis	17	3	13	1	0	38	
	0.7	***0.4***	***0.9***	***0.2***	***0.0***	***0.7***	
Atrial septal defect	508	407	464	122	5	1556	
	21.7	***52.3***	***33.7***	***22.2***	***88.7***	***29.7***	
Atrioventricular septal defect (Endocardial cushion defect)	56	27	39	3	0	130	
	2.4	***3.5***	***2.8***	***0.5***	***0.0***	***2.5***	
Biliary atresia	10	5	13	2	0	31	
	0.4	***0.6***	***0.9***	***0.4***	***0.0***	***0.6***	
Bladder exstrophy	3	0	3	0	0	8	
	0.1	***0.0***	***0.2***	***0.0***	***0.0***	***0.2***	
Choanal atresia	27	12	17	1	0	58	
	1.2	***1.5***	***1.2***	***0.2***	***0.0***	***1.1***	
Cleft lip alone	69	16	53	13	0	159	
	2.9	***2.1***	***3.8***	***2.4***	***0.0***	***3.0***	
Cleft lip with cleft palate	83	21	59	18	1	186	
	3.5	***2.7***	***4.3***	***3.3***	***17.7***	***3.6***	
Cleft palate alone	136	24	78	43	0	290	
	5.8	***3.1***	***5.7***	***7.8***	***0.0***	***5.5***	
Cloacal exstrophy	49	19	42	13	0	126	
	2.1	***2.4***	***3.1***	***2.4***	***0.0***	***2.4***	
Clubfoot	231	96	137	44	1	531	
	9.9	***12.3***	***9.9***	***8.0***	***17.7***	***10.2***	
Coarctation of the aorta	84	18	47	12	1	175	
	3.6	***2.3***	***3.4***	***2.2***	***17.7***	***3.3***	
Common truncus (truncus arteriosus)	8	5	6	1	0	23	
	0.3	***0.6***	***0.4***	***0.2***	***0.0***	***0.4***	
Congenital cataract	32	17	37	7	1	97	
	1.4	***2.2***	***2.7***	***1.3***	***17.7***	***1.9***	
Congenital posterior urethral valves	22	14	11	4	0	54	
	0.9	***1.8***	***0.8***	***0.7***	***0.0***	***1.0***	
Deletion 22q11.2	4	1	2	0	0	7	
	0.2	***0.1***	***0.1***	***0.0***	***0.0***	***0.1***	
Diaphragmatic hernia	31	4	30	7	0	75	
	1.3	***0.5***	***2.2***	***1.3***	***0.0***	***1.4***	
Double outlet right ventricle	10	19	19	5	0	57	
	0.4	***2.4***	***1.4***	***0.9***	***0.0***	***1.1***	
Ebstein anomaly	18	3	9	1	1	33	
	0.8	***0.4***	***0.7***	***0.2***	***17.7***	***0.6***	
Encephalocele	10	4	3	2	0	21	
	0.4	***0.5***	***0.2***	***0.4***	***0.0***	***0.4***	
Esophageal atresia/tracheoesophageal fistula	59	18	30	11	0	126	
	2.5	***2.3***	***2.2***	***2.0***	***0.0***	***2.4***	
Gastroschisis	44	18	41	3	2	113	
	1.9	***2.3***	***3.0***	***0.5***	***35.5***	***2.2***	
Holoprosencephaly	82	43	82	8	0	228	
	3.5	***5.5***	***6.0***	***1.5***	***0.0***	***4.4***	
Hypoplastic left heart syndrome	28	12	16	0	0	61	
	1.2	***1.5***	***1.2***	***0.0***	***0.0***	***1.2***	
Hypospadias*	1148	265	378	159	4	2024	
	95.7	***66.9***	***54.0***	***56.2***	***134.2***	***75.7***	
Interrupted aortic arch	8	9	8	1	0	26	
	0.3	***1.2***	***0.6***	***0.2***	***0.0***	***0.5***	
Limb deficiencies (reduction defects)	97	48	66	13	0	238	
	4.1	***6.2***	***4.8***	***2.4***	***0.0***	***4.5***	

New Jersey
Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	18	14	13	4	0	50	
	0.8	***1.8***	***0.9***	***0.7***	***0.0***	***1.0***	
Pulmonary valve atresia and stenosis	157	84	121	27	1	413	
	6.7	***10.8***	***8.8***	***4.9***	***17.7***	***7.9***	
Pulmonary valve atresia	10	9	15	2	0	42	
	0.4	***1.2***	***1.1***	***0.4***	***0.0***	***0.8***	
Rectal and large intestinal atresia/stenosis	67	24	53	19	1	174	
	2.9	***3.1***	***3.8***	***3.5***	***17.7***	***3.3***	
Renal agenesis/hypoplasia	144	30	73	23	1	282	
	6.2	***3.9***	***5.3***	***4.2***	***17.7***	***5.4***	
Single ventricle	5	4	2	3	0	14	
	0.2	***0.5***	***0.1***	***0.5***	***0.0***	***0.3***	
Small intestinal atresia/stenosis	67	27	47	10	0	154	
	2.9	***3.5***	***3.4***	***1.8***	***0.0***	***2.9***	
Spina bifida without anencephalus	44	21	46	8	0	128	
	1.9	***2.7***	***3.3***	***1.5***	***0.0***	***2.4***	
Tetralogy of Fallot	60	32	46	15	0	170	
	2.6	***4.1***	***3.3***	***2.7***	***0.0***	***3.2***	
Total anomalous pulmonary venous connection	6	7	20	2	0	35	
	0.3	***0.9***	***1.5***	***0.4***	***0.0***	***0.7***	
Transposition of the great arteries (TGA)	40	20	25	9	0	100	
	1.7	***2.6***	***1.8***	***1.6***	***0.0***	***1.9***	
Dextro-transposition of great arteries (d-TGA)	26	13	14	7	0	62	
	1.1	***1.7***	***1.0***	***1.3***	***0.0***	***1.2***	
Tricuspid valve atresia and stenosis	194	116	188	24	0	529	
	8.3	***14.9***	***13.7***	***4.4***	***0.0***	***10.1***	
Trisomy 13	4	6	7	0	0	19	
	0.2	***0.8***	***0.5***	***0.0***	***0.0***	***0.4***	
Trisomy 18	18	16	9	2	0	45	
	0.8	***2.1***	***0.7***	***0.4***	***0.0***	***0.9***	
Trisomy 21 (Down syndrome)	252	91	218	30	2	618	
	10.8	***11.7***	***15.8***	***5.5***	***35.5***	***11.8***	
Turner syndrome†	10	2	4	1	0	18	
	0.9	***0.5***	***0.6***	***0.4***	***0.0***	***0.7***	
Ventricular septal defect	1271	426	843	237	2	2867	
	54.3	***54.8***	***61.2***	***43.2***	***35.5***	***54.8***	
Total live births §	**234055**	**77784**	**137697**	**54916**	**564**	**523109**	
Male live births	**119922**	**39610**	**69974**	**28306**	**298**	**267459**	
Female live births	**114133**	**38171**	**67722**	**26610**	**266**	**255646**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births. Excludes male phenotype.
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

New Jersey

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	106	4	113	
	2.6	***0.4***	***2.2***	
Trisomy 13	13	6	19	
	0.3	***0.5***	***0.4***	
Trisomy 18	20	24	45	
	0.5	***2.1***	***0.9***	
Trisomy 21 (Down syndrome)	267	322	618	
	6.5	***28.8***	***11.8***	
Total live births	**411148**	**111868**	**523109**	

**Total includes unknown maternal age

New Mexico

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	9	0	19	1	4	35	
	2.5	***0.0***	***2.7***	***3.9***	***2.4***	***2.7***	
Cleft lip alone	5	0	26	0	6	39	
	1.4	***0.0***	***3.6***	***0.0***	***3.6***	***3.0***	
Cleft lip with cleft palate	20	1	49	0	17	88	
	5.5	***4.4***	***6.9***	***0.0***	***10.2***	***6.8***	
Cleft palate alone	32	3	50	2	13	101	
	8.9	***13.2***	***7.0***	***7.7***	***7.8***	***7.8***	
Common truncus (truncus arteriosus)	0	0	1	0	0	1	
	0.0	***0.0***	***0.1***	***0.0***	***0.0***	***0.1***	
Gastroschisis	12	2	54	2	10	82	
	3.3	***8.8***	***7.6***	***7.7***	***6.0***	***6.3***	
Hypoplastic left heart syndrome	6	0	9	0	4	20	
	1.7	***0.0***	***1.3***	***0.0***	***2.4***	***1.5***	
Hypospadias*	129	10	125	4	13	286	
	69.3	***87.4***	***34.5***	***30.6***	***15.5***	***43.1***	
Limb deficiencies (reduction defects)	26	1	54	2	9	96	
	7.2	***4.4***	***7.6***	***7.7***	***5.4***	***7.4***	
Renal agenesis/hypoplasia	2	0	13	0	2	17	
	0.6	***0.0***	***1.8***	***0.0***	***1.2***	***1.3***	
Spina bifida without anencephalus	26	1	46	0	12	85	
	7.2	***4.4***	***6.5***	***0.0***	***7.2***	***6.5***	
Tetralogy of Fallot	8	1	18	3	6	36	
	2.2	***4.4***	***2.5***	***11.6***	***3.6***	***2.8***	
Transposition of the great arteries (TGA)	3	2	11	0	3	19	
	0.8	***8.8***	***1.5***	***0.0***	***1.8***	***1.5***	
Trisomy 13	4	2	9	1	2	26	
	1.1	***8.8***	***1.3***	***3.9***	***1.2***	***2.0***	
Trisomy 18	5	3	9	1	4	47	
	1.4	***13.2***	***1.3***	***3.9***	***2.4***	***3.6***	
Trisomy 21 (Down syndrome)	43	3	91	1	17	172	
	11.9	***13.2***	***12.8***	***3.9***	***10.2***	***13.2***	
Total live births	**36152**	**2268**	**71317**	**2597**	**16646**	**130274**	
Male live births	**18616**	**1144**	**36200**	**1306**	**8404**	**66334**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

New Mexico

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	80	1	82	
	6.9	***0.7***	***6.3***	
Trisomy 13	14	4	26	
	1.2	***2.9***	***2.0***	
Trisomy 18	16	6	47	
	1.4	***4.3***	***3.6***	
Trisomy 21 (Down syndrome)	98	61	172	
	8.4	***43.5***	***13.2***	
Total live births	**116248**	**14026**	**130274**	

**Total includes unknown maternal age

General comments
-Unspecified non-livebirths include terminations plus spontaneous abortions.

New York

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	15	5	10	3	0	34	
	0.2	***0.3***	***0.3***	***0.2***	***0.0***	***0.3***	
Anophthalmia/microphthalmia	52	23	36	12	0	123	
	0.9	***1.2***	***1.3***	***1.0***	***0.0***	***1.0***	
Anotia/microtia	60	17	64	30	2	174	
	1.0	***0.9***	***2.2***	***2.4***	***9.2***	***1.4***	
Aortic valve stenosis	111	16	41	15	0	186	
	1.8	***0.8***	***1.4***	***1.2***	***0.0***	***1.5***	
Atrial septal defect	2368	1732	1803	808	6	6816	
	38.7	***89.0***	***62.9***	***65.2***	***27.5***	***55.5***	
Atrioventricular septal defect (Endocardial cushion defect)	245	120	123	51	2	548	
	4.0	***6.2***	***4.3***	***4.1***	***9.2***	***4.5***	
Biliary atresia	53	39	26	24	1	145	
	0.9	***2.0***	***0.9***	***1.9***	***4.6***	***1.2***	
Bladder exstrophy	15	1	4	1	0	21	
	0.2	***0.1***	***0.1***	***0.1***	***0.0***	***0.2***	
Choanal atresia	121	34	47	12	0	215	
	2.0	***1.7***	***1.6***	***1.0***	***0.0***	***1.8***	
Cleft lip alone	167	27	46	30	1	277	
	2.7	***1.4***	***1.6***	***2.4***	***4.6***	***2.3***	
Cleft lip with cleft palate	299	67	133	69	4	578	
	4.9	***3.4***	***4.6***	***5.6***	***18.3***	***4.7***	
Cleft palate alone	374	80	135	97	1	695	
	6.1	***4.1***	***4.7***	***7.8***	***4.6***	***5.7***	
Cloacal exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Clubfoot	934	276	366	182	3	1777	
	15.3	***14.2***	***12.8***	***14.7***	***13.7***	***14.5***	
Coarctation of the aorta	331	82	147	69	2	638	
	5.4	***4.2***	***5.1***	***5.6***	***9.2***	***5.2***	
Common truncus (truncus arteriosus)	36	11	11	9	0	68	
	0.6	***0.6***	***0.4***	***0.7***	***0.0***	***0.6***	
Congenital cataract	113	39	65	25	0	246	
	1.8	***2.0***	***2.3***	***2.0***	***0.0***	***2.0***	
Congenital posterior urethral valves	54	47	25	14	0	141	
	0.9	***2.4***	***0.9***	***1.1***	***0.0***	***1.1***	
Craniosynostosis	378	53	137	40	2	620	
	6.2	***2.7***	***4.8***	***3.2***	***9.2***	***5.0***	
Deletion 22q11.2	21	6	7	2	0	38	
	0.3	***0.3***	***0.2***	***0.2***	***0.0***	***0.3***	
Diaphragmatic hernia	144	43	56	36	0	286	
	2.4	***2.2***	***2.0***	***2.9***	***0.0***	***2.3***	
Double outlet right ventricle	88	49	64	43	0	250	
	1.4	***2.5***	***2.2***	***3.5***	***0.0***	***2.0***	
Ebstein anomaly	34	14	27	8	0	85	
	0.6	***0.7***	***0.9***	***0.6***	***0.0***	***0.7***	
Encephalocele	35	20	18	10	0	85	
	0.6	***1.0***	***0.6***	***0.8***	***0.0***	***0.7***	
Esophageal atresia/tracheoesophageal fistula	139	33	61	23	0	264	
	2.3	***1.7***	***2.1***	***1.9***	***0.0***	***2.1***	
Gastroschisis	159	44	65	13	0	286	
	2.6	***2.3***	***2.3***	***1.0***	***0.0***	***2.3***	
Holoprosencephaly	36	14	19	1	0	71	
	0.6	***0.7***	***0.7***	***0.1***	***0.0***	***0.6***	
Hypoplastic left heart syndrome	146	53	68	24	1	294	
	2.4	***2.7***	***2.4***	***1.9***	***4.6***	***2.4***	
Hypospadias*	2906	749	695	364	7	4770	
	92.5	***75.6***	***47.7***	***56.8***	***63.8***	***75.8***	
Interrupted aortic arch	49	15	26	8	0	98	
	0.8	***0.8***	***0.9***	***0.6***	***0.0***	***0.8***	

New York

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	185	68	77	24	0	357	
	3.0	***3.5***	***2.7***	***1.9***	***0.0***	***2.9***	
Omphalocele	88	23	26	10	2	150	
	1.4	***1.2***	***0.9***	***0.8***	***9.2***	***1.2***	
Pulmonary valve atresia and stenosis	454	196	223	113	1	1001	
	7.4	***10.1***	***7.8***	***9.1***	***4.6***	***8.1***	
Pulmonary valve atresia	51	17	28	20	0	118	
	0.8	***0.9***	***1.0***	***1.6***	***0.0***	***1.0***	
Rectal and large intestinal atresia/stenosis	219	66	108	65	1	468	
	3.6	***3.4***	***3.8***	***5.2***	***4.6***	***3.8***	
Renal agenesis/hypoplasia	322	74	128	58	1	593	
	5.3	***3.8***	***4.5***	***4.7***	***4.6***	***4.8***	
Single ventricle	45	13	24	14	0	98	
	0.7	***0.7***	***0.8***	***1.1***	***0.0***	***0.8***	
Small intestinal atresia/stenosis	242	108	101	59	1	517	
	4.0	***5.5***	***3.5***	***4.8***	***4.6***	***4.2***	
Spina bifida without anencephalus	152	37	72	21	2	288	
	2.5	***1.9***	***2.5***	***1.7***	***9.2***	***2.3***	
Tetralogy of Fallot	292	100	128	115	1	646	
	4.8	***5.1***	***4.5***	***9.3***	***4.6***	***5.3***	
Total anomalous pulmonary venous connection	55	26	43	25	0	150	
	0.9	***1.3***	***1.5***	***2.0***	***0.0***	***1.2***	
Transposition of the great arteries (TGA)	180	28	66	42	0	322	
	2.9	***1.4***	***2.3***	***3.4***	***0.0***	***2.6***	
Dextro-transposition of great arteries (d-TGA)	172	28	66	40	0	312	
	2.8	***1.4***	***2.3***	***3.2***	***0.0***	***2.5***	
Tricuspid valve atresia and stenosis	77	31	38	25	0	177	
	1.3	***1.6***	***1.3***	***2.0***	***0.0***	***1.4***	
Tricuspid valve atresia	56	14	16	15	0	102	
	0.9	***0.7***	***0.6***	***1.2***	***0.0***	***0.8***	
Trisomy 13	23	23	15	9	0	71	
	0.4	***1.2***	***0.5***	***0.7***	***0.0***	***0.6***	
Trisomy 18	56	38	38	14	0	146	
	0.9	***2.0***	***1.3***	***1.1***	***0.0***	***1.2***	
Trisomy 21 (Down syndrome)	701	261	380	153	2	1518	
	11.5	***13.4***	***13.3***	***12.3***	***9.2***	***12.4***	
Turner syndrome†	49	13	20	9	0	93	
	1.6	***1.4***	***1.4***	***1.5***	***0.0***	***1.6***	
Ventricular septal defect	2868	856	1301	687	10	5799	
	46.9	***44.0***	***45.4***	***55.4***	***45.8***	***47.2***	
Total live births §	**611097**	**194618**	**286642**	**124002**	**2185**	**1228354**	
Male live births	**314058**	**99012**	**145775**	**64062**	**1097**	**629099**	
Female live births	**297030**	**95606**	**140866**	**59939**	**1088**	**599244**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

New York

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	277	9	286	
	2.8	***0.4***	***2.3***	
Trisomy 13	45	26	71	
	0.5	***1.0***	***0.6***	
Trisomy 18	79	67	146	
	0.8	***2.7***	***1.2***	
Trisomy 21 (Down syndrome)	736	782	1518	
	7.5	***31.1***	***12.4***	
Total live births	**977100**	**251179**	**1228354**	

**Total includes unknown maternal age

North Carolina

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	92	26	35	4	4	182	
	2.7	***1.8***	***3.8***	***1.9***	***4.7***	***3.0***	
Anophthalmia/microphthalmia	59	24	20	4	1	110	
	1.7	***1.7***	***2.2***	***1.9***	***1.2***	***1.8***	
Anotia/microtia	45	13	42	3	6	110	
	1.3	***0.9***	***4.5***	***1.4***	***7.1***	***1.8***	
Aortic valve stenosis	90	28	16	2	1	137	
	2.7	***1.9***	***1.7***	***0.9***	***1.2***	***2.3***	
Atrial septal defect	1828	957	483	88	70	3439	
	53.8	***66.0***	***52.2***	***41.1***	***83.1***	***56.5***	
Atrioventricular septal defect (Endocardial cushion defect)	225	100	57	11	7	408	
	6.6	***6.9***	***6.2***	***5.1***	***8.3***	***6.7***	
Biliary atresia	19	10	4	1	0	34	
	0.6	***0.7***	***0.4***	***0.5***	***0.0***	***0.6***	
Bladder exstrophy	10	7	3	0	0	20	
	0.3	***0.5***	***0.3***	***0.0***	***0.0***	***0.3***	
Choanal atresia	46	15	17	3	1	82	
	1.4	***1.0***	***1.8***	***1.4***	***1.2***	***1.3***	
Cleft lip alone	122	50	23	5	5	208	
	3.6	***3.5***	***2.5***	***2.3***	***5.9***	***3.4***	
Cleft lip with cleft palate	212	55	60	13	8	350	
	6.2	***3.8***	***6.5***	***6.1***	***9.5***	***5.8***	
Cleft palate alone	263	51	35	10	6	367	
	7.7	***3.5***	***3.8***	***4.7***	***7.1***	***6.0***	
Cloacal exstrophy	11	7	5	0	0	23	
	0.3	***0.5***	***0.5***	***0.0***	***0.0***	***0.4***	
Clubfoot	694	274	173	28	15	1197	
	20.4	***18.9***	***18.7***	***13.1***	***17.8***	***19.7***	
Coarctation of the aorta	192	57	35	8	1	294	
	5.7	***3.9***	***3.8***	***3.7***	***1.2***	***4.8***	
Common truncus (truncus arteriosus)	22	8	7	3	0	41	
	0.6	***0.6***	***0.8***	***1.4***	***0.0***	***0.7***	
Congenital cataract	25	21	9	2	0	57	
	0.7	***1.4***	***1.0***	***0.9***	***0.0***	***0.9***	
Congenital posterior urethral valves	84	44	16	2	3	150	
	2.5	***3.0***	***1.7***	***0.9***	***3.6***	***2.5***	
Craniosynostosis	270	47	46	8	5	377	
	8.0	***3.2***	***5.0***	***3.7***	***5.9***	***6.2***	
Diaphragmatic hernia	108	31	28	6	3	180	
	3.2	***2.1***	***3.0***	***2.8***	***3.6***	***3.0***	
Double outlet right ventricle	58	25	12	0	2	98	
	1.7	***1.7***	***1.3***	***0.0***	***2.4***	***1.6***	
Ebstein anomaly	26	9	5	2	1	43	
	0.8	***0.6***	***0.5***	***0.9***	***1.2***	***0.7***	
Encephalocele	31	20	14	0	2	74	
	0.9	***1.4***	***1.5***	***0.0***	***2.4***	***1.2***	
Esophageal atresia/tracheoesophageal fistula	104	32	20	1	1	158	
	3.1	***2.2***	***2.2***	***0.5***	***1.2***	***2.6***	
Gastroschisis	177	59	32	3	7	280	
	5.2	***4.1***	***3.5***	***1.4***	***8.3***	***4.6***	
Holoprosencephaly	36	23	22	3	2	89	
	1.1	***1.6***	***2.4***	***1.4***	***2.4***	***1.5***	
Hypoplastic left heart syndrome	87	32	24	4	0	149	
	2.6	***2.2***	***2.6***	***1.9***	***0.0***	***2.4***	
Hypospadias*	1128	379	112	60	30	1711	
	64.8	***51.6***	***23.8***	***54.2***	***70.0***	***55.1***	
Interrupted aortic arch	18	16	7	3	0	44	
	0.5	***1.1***	***0.8***	***1.4***	***0.0***	***0.7***	
Limb deficiencies (reduction defects)	165	80	40	6	7	304	
	4.9	***5.5***	***4.3***	***2.8***	***8.3***	***5.0***	

North Carolina

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	70	53	23	8	2	162	
	2.1	***3.7***	***2.5***	***3.7***	***2.4***	***2.7***	
Pulmonary valve atresia and stenosis	257	138	63	15	11	488	
	7.6	***9.5***	***6.8***	***7.0***	***13.1***	***8.0***	
Pulmonary valve atresia	50	32	8	6	2	99	
	1.5	***2.2***	***0.9***	***2.8***	***2.4***	***1.6***	
Rectal and large intestinal atresia/stenosis	144	53	48	8	5	260	
	4.2	***3.7***	***5.2***	***3.7***	***5.9***	***4.3***	
Renal agenesis/hypoplasia	221	79	52	4	5	368	
	6.5	***5.5***	***5.6***	***1.9***	***5.9***	***6.1***	
Single ventricle	30	14	13	2	0	59	
	0.9	***1.0***	***1.4***	***0.9***	***0.0***	***1.0***	
Small intestinal atresia/stenosis	95	46	37	9	3	190	
	2.8	***3.2***	***4.0***	***4.2***	***3.6***	***3.1***	
Spina bifida without anencephalus	146	43	44	5	3	248	
	4.3	***3.0***	***4.8***	***2.3***	***3.6***	***4.1***	
Tetralogy of Fallot	143	70	33	12	6	266	
	4.2	***4.8***	***3.6***	***5.6***	***7.1***	***4.4***	
Total anomalous pulmonary venous connection	36	15	18	3	1	73	
	1.1	***1.0***	***1.9***	***1.4***	***1.2***	***1.2***	
Transposition of the great arteries (TGA)	118	43	21	6	5	195	
	3.5	***3.0***	***2.3***	***2.8***	***5.9***	***3.2***	
Dextro-transposition of great arteries (d-TGA)	85	21	12	6	5	130	
	2.5	***1.4***	***1.3***	***2.8***	***5.9***	***2.1***	
Tricuspid valve atresia and stenosis	78	54	22	4	6	165	
	2.3	***3.7***	***2.4***	***1.9***	***7.1***	***2.7***	
Tricuspid valve atresia	68	48	18	4	6	145	
	2.0	***3.3***	***1.9***	***1.9***	***7.1***	***2.4***	
Trisomy 13	32	31	17	3	1	88	
	0.9	***2.1***	***1.8***	***1.4***	***1.2***	***1.4***	
Trisomy 18	111	50	35	5	1	210	
	3.3	***3.5***	***3.8***	***2.3***	***1.2***	***3.5***	
Trisomy 21 (Down syndrome)	443	127	144	26	14	775	
	13.0	***8.8***	***15.6***	***12.2***	***16.6***	***12.7***	
Turner syndrome†	40	7	9	0	0	60	
	2.4	***1.0***	***2.0***	***0.0***	***0.0***	***2.0***	
Ventricular septal defect	1512	593	479	76	32	2703	
	44.5	***40.9***	***51.8***	***35.5***	***38.0***	***44.4***	
Total live births §	**339507**	**144892**	**92560**	**21395**	**8422**	**608240**	
Male live births	**174045**	**73397**	**47093**	**11078**	**4288**	**310658**	
Female live births	**165460**	**71494**	**45463**	**10317**	**4134**	**297575**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

North Carolina

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	270	9	280	
	5.1	***1.1***	***4.6***	
Trisomy 13	58	30	88	
	1.1	***3.7***	***1.4***	
Trisomy 18	117	91	210	
	2.2	***11.3***	***3.5***	
Trisomy 21 (Down syndrome)	406	366	775	
	7.7	***45.3***	***12.7***	
Total live births	**527334**	**80875**	**608240**	

**Total includes unknown maternal age

General comments
-Fetal deaths are defined as deaths at 20 or more weeks gestation.
-Terminations are defined as termination of pregnancy before 20 weeks gestation and do not include intra-uterine fetal death before 20 weeks.

North Dakota

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	19	1	0	0	3	23	
	4.9	***9.5***	***0.0***	***0.0***	***6.7***	***4.8***	
Anophthalmia/microphthalmia	0	0	0	1	0	1	
	0.0	***0.0***	***0.0***	***13.3***	***0.0***	***0.2***	
Anotia/microtia	5	0	0	0	1	6	
	1.3	***0.0***	***0.0***	***0.0***	***2.2***	***1.3***	
Aortic valve stenosis	6	0	0	0	2	8	
	1.5	***0.0***	***0.0***	***0.0***	***4.4***	***1.7***	
Atrial septal defect	335	24	0	6	110	491	
	86.3	***226.8***	***0.0***	***79.9***	***244.2***	***102.4***	
Atrioventricular septal defect (Endocardial cushion defect)	19	0	0	1	1	21	
	4.9	***0.0***	***0.0***	***13.3***	***2.2***	***4.4***	
Biliary atresia	2	0	0	0	0	2	
	0.5	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Bladder exstrophy	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Choanal atresia	3	0	0	0	0	3	
	0.8	***0.0***	***0.0***	***0.0***	***0.0***	***0.6***	
Cleft lip alone	47	0	0	2	10	62	
	12.1	***0.0***	***0.0***	***26.6***	***22.2***	***12.9***	
Cleft lip with cleft palate	29	0	0	3	19	51	
	7.5	***0.0***	***0.0***	***39.9***	***42.2***	***10.6***	
Cleft palate alone	62	0	0	3	14	80	
	16.0	***0.0***	***0.0***	***39.9***	***31.1***	***16.7***	
Cloacal exstrophy	1	0	0	0	0	1	1
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Coarctation of the aorta	15	1	0	0	2	18	
	3.9	***9.5***	***0.0***	***0.0***	***4.4***	***3.8***	
Common truncus (truncus arteriosus)	5	0	0	0	1	6	
	1.3	***0.0***	***0.0***	***0.0***	***2.2***	***1.3***	
Congenital cataract	5	1	0	0	0	7	
	1.3	***9.5***	***0.0***	***0.0***	***0.0***	***1.5***	
Diaphragmatic hernia	13	0	0	0	3	16	
	3.3	***0.0***	***0.0***	***0.0***	***6.7***	***3.3***	
Double outlet right ventricle	1	0	0	0	0	2	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Ebstein anomaly	6	1	0	0	0	7	
	1.5	***9.5***	***0.0***	***0.0***	***0.0***	***1.5***	
Encephalocele	1	0	0	0	1	3	
	0.3	***0.0***	***0.0***	***0.0***	***2.2***	***0.6***	
Esophageal atresia/tracheoesophageal fistula	7	1	0	0	0	8	
	1.8	***9.5***	***0.0***	***0.0***	***0.0***	***1.7***	
Gastroschisis	14	0	0	0	9	23	
	3.6	***0.0***	***0.0***	***0.0***	***20.0***	***4.8***	
Holoprosencephaly	1	0	0	0	1	2	1
	0.3	***0.0***	***0.0***	***0.0***	***2.2***	***0.4***	
Hypoplastic left heart syndrome	12	0	0	0	1	15	
	3.1	***0.0***	***0.0***	***0.0***	***2.2***	***3.1***	
Hypospadias*	67	3	0	1	7	80	
	33.9	***52.4***	***0.0***	***25.3***	***30.3***	***32.7***	
Limb deficiencies (reduction defects)	6	0	0	0	3	9	
	1.5	***0.0***	***0.0***	***0.0***	***6.7***	***1.9***	
Omphalocele	5	0	0	0	1	6	
	1.3	***0.0***	***0.0***	***0.0***	***2.2***	***1.3***	
Pulmonary valve atresia and stenosis	53	4	0	1	15	80	
	13.7	***37.8***	***0.0***	***13.3***	***33.3***	***16.7***	
Pulmonary valve atresia	5	0	0	0	2	9	
	1.3	***0.0***	***0.0***	***0.0***	***4.4***	***1.9***	
Rectal and large intestinal atresia/stenosis	9	1	0	0	0	11	
	2.3	***9.5***	***0.0***	***0.0***	***0.0***	***2.3***	

North Dakota

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Renal agenesis/hypoplasia	4	1	0	0	7	12	
	1.0	***9.5***	***0.0***	***0.0***	***15.5***	***2.5***	
Single ventricle	1	0	0	0	1	2	
	0.3	***0.0***	***0.0***	***0.0***	***2.2***	***0.4***	
Small intestinal atresia/stenosis	1	0	0	0	0	1	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Spina bifida without anencephalus	19	0	0	0	5	30	
	4.9	***0.0***	***0.0***	***0.0***	***11.1***	***6.3***	
Tetralogy of Fallot	12	0	0	0	4	17	
	3.1	***0.0***	***0.0***	***0.0***	***8.9***	***3.5***	
Total anomalous pulmonary venous connection	0	0	0	0	1	1	
	0.0	***0.0***	***0.0***	***0.0***	***2.2***	***0.2***	
Transposition of the great arteries (TGA)	10	0	0	0	2	13	
	2.6	***0.0***	***0.0***	***0.0***	***4.4***	***2.7***	
Dextro-transposition of great arteries (d-TGA)	6	0	0	0	2	9	
	1.5	***0.0***	***0.0***	***0.0***	***4.4***	***1.9***	
Tricuspid valve atresia and stenosis	2	0	0	0	1	4	
	0.5	***0.0***	***0.0***	***0.0***	***2.2***	***0.8***	
Tricuspid valve atresia	2	0	0	0	1	4	
	0.5	***0.0***	***0.0***	***0.0***	***2.2***	***0.8***	
Trisomy 13	1	0	0	0	0	1	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Trisomy 18	3	0	0	0	3	6	
	0.8	***0.0***	***0.0***	***0.0***	***6.7***	***1.3***	
Trisomy 21 (Down syndrome)	43	1	0	2	3	53	
	11.1	***9.5***	***0.0***	***26.6***	***6.7***	***11.1***	
Turner syndrome†	1	0	0	1	0	2	
	0.5	***0.0***	***0.0***	***28.2***	***0.0***	***0.9***	
Ventricular septal defect	131	5	0	3	38	187	2
	33.7	***47.3***	***0.0***	***39.9***	***84.4***	***39.0***	
Total live births §	**38816**	**1058**	**1720**	**751**	**4504**	**47959**	
Male live births	**19749**	**573**	**880**	**396**	**2313**	**24452**	
Female live births	**19066**	**485**	**840**	**355**	**2189**	**23504**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

North Dakota

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	20	0	23	
	4.7	***0.0***	***4.8***	
Trisomy 13	1	0	1	
	0.2	***0.0***	***0.2***	
Trisomy 18	5	0	6	
	1.2	***0.0***	***1.3***	
Trisomy 21 (Down syndrome)	30	23	53	
	7.0	***48.6***	***11.1***	
Total live births	**42939**	**4737**	**47959**	

**Total includes unknown maternal age

Notes
1.Data for this condition begin in 2013.
2.Data for this condition exclude inlet ventricular septal defect and common atrioventricular canal type ventricular septal defect.

General comments
-Fetal Death reporting not required before 20 weeks gestation. North Dakota does not differentiate between fetal deaths and terminations.

Oklahoma

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	38	4	9	0	7	58	
	2.3	***1.6***	***2.3***	***0.0***	***2.4***	***2.2***	
Anophthalmia/microphthalmia	22	0	4	1	6	33	
	1.3	***0.0***	***1.0***	***1.4***	***2.1***	***1.2***	
Anotia/microtia	28	2	14	3	3	50	
	1.7	***0.8***	***3.6***	***4.3***	***1.0***	***1.9***	
Aortic valve stenosis	62	3	14	0	4	83	
	3.7	***1.2***	***3.6***	***0.0***	***1.4***	***3.1***	
Atrial septal defect	1091	164	185	21	183	1655	
	65.6	***67.3***	***47.0***	***30.0***	***63.5***	***62.2***	
Atrioventricular septal defect (Endocardial cushion defect)	87	20	21	2	10	141	
	5.2	***8.2***	***5.3***	***2.9***	***3.5***	***5.3***	
Biliary atresia	11	3	2	0	4	20	
	0.7	***1.2***	***0.5***	***0.0***	***1.4***	***0.8***	
Bladder exstrophy	5	1	0	0	2	8	
	0.3	***0.4***	***0.0***	***0.0***	***0.7***	***0.3***	
Choanal atresia	27	5	4	0	2	38	
	1.6	***2.1***	***1.0***	***0.0***	***0.7***	***1.4***	
Cleft lip alone	73	8	11	2	11	107	
	4.4	***3.3***	***2.8***	***2.9***	***3.8***	***4.0***	
Cleft lip with cleft palate	143	10	26	3	26	213	
	8.6	***4.1***	***6.6***	***4.3***	***9.0***	***8.0***	
Cleft palate alone	137	14	25	9	20	209	
	8.2	***5.7***	***6.4***	***12.8***	***6.9***	***7.9***	
Clubfoot	313	25	66	5	52	472	
	18.8	***10.3***	***16.8***	***7.1***	***18.0***	***17.7***	
Coarctation of the aorta	87	11	17	1	16	133	
	5.2	***4.5***	***4.3***	***1.4***	***5.6***	***5.0***	
Common truncus (truncus arteriosus)	7	4	1	0	3	18	
	0.4	***1.6***	***0.3***	***0.0***	***1.0***	***0.7***	
Congenital cataract	25	3	3	1	2	35	
	1.5	***1.2***	***0.8***	***1.4***	***0.7***	***1.3***	
Congenital posterior urethral valves	21	5	1	0	2	30	
	1.3	***2.1***	***0.3***	***0.0***	***0.7***	***1.1***	
Craniosynostosis	55	4	8	2	9	82	
	3.3	***1.6***	***2.0***	***2.9***	***3.1***	***3.1***	
Deletion 22q11.2	16	3	2	0	5	26	
	1.0	***1.2***	***0.5***	***0.0***	***1.7***	***1.0***	
Diaphragmatic hernia	58	4	21	2	10	96	
	3.5	***1.6***	***5.3***	***2.9***	***3.5***	***3.6***	
Double outlet right ventricle	32	9	5	2	9	57	
	1.9	***3.7***	***1.3***	***2.9***	***3.1***	***2.1***	
Ebstein anomaly	13	0	6	1	0	21	
	0.8	***0.0***	***1.5***	***1.4***	***0.0***	***0.8***	
Encephalocele	13	6	3	0	6	28	
	0.8	***2.5***	***0.8***	***0.0***	***2.1***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	44	3	9	1	9	66	
	2.6	***1.2***	***2.3***	***1.4***	***3.1***	***2.5***	
Gastroschisis	91	9	18	3	18	139	
	5.5	***3.7***	***4.6***	***4.3***	***6.2***	***5.2***	
Holoprosencephaly	19	2	6	0	5	32	
	1.1	***0.8***	***1.5***	***0.0***	***1.7***	***1.2***	
Hypoplastic left heart syndrome	42	1	11	1	6	62	
	2.5	***0.4***	***2.8***	***1.4***	***2.1***	***2.3***	
Hypospadias*	342	47	17	7	43	461	
	39.9	***38.0***	***8.5***	***19.8***	***29.4***	***33.8***	
Interrupted aortic arch	14	3	3	0	3	23	
	0.8	***1.2***	***0.8***	***0.0***	***1.0***	***0.9***	
Limb deficiencies (reduction defects)	85	12	14	1	12	125	
	5.1	***4.9***	***3.6***	***1.4***	***4.2***	***4.7***	

Oklahoma

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	37	9	9	0	4	59	
	2.2	***3.7***	***2.3***	***0.0***	***1.4***	***2.2***	
Pulmonary valve atresia and stenosis	153	21	26	5	13	222	
	9.2	***8.6***	***6.6***	***7.1***	***4.5***	***8.3***	
Pulmonary valve atresia	19	4	4	2	4	34	
	1.1	***1.6***	***1.0***	***2.9***	***1.4***	***1.3***	
Rectal and large intestinal atresia/stenosis	99	11	25	5	13	156	
	5.9	***4.5***	***6.4***	***7.1***	***4.5***	***5.9***	
Renal agenesis/hypoplasia	102	8	16	1	13	142	
	6.1	***3.3***	***4.1***	***1.4***	***4.5***	***5.3***	
Single ventricle	7	1	2	0	0	12	
	0.4	***0.4***	***0.5***	***0.0***	***0.0***	***0.5***	
Small intestinal atresia/stenosis	74	9	11	0	9	105	
	4.4	***3.7***	***2.8***	***0.0***	***3.1***	***3.9***	
Spina bifida without anencephalus	56	5	13	0	9	85	
	3.4	***2.1***	***3.3***	***0.0***	***3.1***	***3.2***	
Tetralogy of Fallot	77	10	10	5	13	116	
	4.6	***4.1***	***2.5***	***7.1***	***4.5***	***4.4***	
Total anomalous pulmonary venous connection	21	2	6	1	5	35	
	1.3	***0.8***	***1.5***	***1.4***	***1.7***	***1.3***	
Transposition of the great arteries (TGA)	56	8	14	1	10	94	
	3.4	***3.3***	***3.6***	***1.4***	***3.5***	***3.5***	
Dextro-transposition of great arteries (d-TGA)	45	8	11	1	8	76	
	2.7	***3.3***	***2.8***	***1.4***	***2.8***	***2.9***	
Tricuspid valve atresia and stenosis	18	3	4	1	2	29	
	1.1	***1.2***	***1.0***	***1.4***	***0.7***	***1.1***	
Tricuspid valve atresia	11	2	2	0	1	17	
	0.7	***0.8***	***0.5***	***0.0***	***0.3***	***0.6***	
Trisomy 13	13	4	4	0	2	24	
	0.8	***1.6***	***1.0***	***0.0***	***0.7***	***0.9***	
Trisomy 18	34	9	5	2	7	57	
	2.0	***3.7***	***1.3***	***2.9***	***2.4***	***2.1***	
Trisomy 21 (Down syndrome)	202	24	74	8	26	341	
	12.1	***9.8***	***18.8***	***11.4***	***9.0***	***12.8***	
Turner syndrome†	23	2	5	0	2	33	
	2.8	***1.7***	***2.6***	***0.0***	***1.4***	***2.5***	
Ventricular septal defect	1015	132	205	33	140	1551	
	61.0	***54.2***	***52.1***	***47.1***	***48.6***	***58.3***	
Total live births §	**166435**	**24372**	**39331**	**7009**	**28819**	**266089**	
Male live births	**85645**	**12367**	**20116**	**3535**	**14622**	**136352**	
Female live births	**80787**	**12005**	**19214**	**3474**	**14197**	**129733**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Oklahoma

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	136	3	139	
	5.6	***1.3***	***5.2***	
Trisomy 13	18	6	24	
	0.7	***2.6***	***0.9***	
Trisomy 18	35	22	57	
	1.4	***9.5***	***2.1***	
Trisomy 21 (Down syndrome)	194	141	341	
	8.0	***60.9***	***12.8***	
Total live births	**242846**	**23162**	**266089**	

**Total includes unknown maternal age

General comments

-Fetal deaths defined as baby born dead (without a heart rate), at or after 20th gestational week. This includes babies that died during labor.
-Terminations defined as fetus terminated by parental choice prior to 37 weeks. When labor is induced to deliver a fetus who is dead prior to the onset of labor it is not considered an elective termination.

Oregon

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	14	2	7	2	0	26	
	0.9	***4.3***	***1.6***	***1.9***	***0.0***	***1.1***	
Cleft lip alone	48	0	12	2	0	64	
	3.1	***0.0***	***2.7***	***1.9***	***0.0***	***2.8***	
Cleft lip with cleft palate	142	6	41	11	6	214	
	9.1	***12.9***	***9.2***	***10.4***	***21.9***	***9.4***	
Cleft palate alone	155	3	47	7	4	221	
	10.0	***6.5***	***10.5***	***6.6***	***14.6***	***9.7***	
Gastroschisis	67	3	26	6	1	114	
	4.3	***6.5***	***5.8***	***5.7***	***3.7***	***5.0***	
Hypoplastic left heart syndrome	61	2	28	3	1	97	
	3.9	***4.3***	***6.3***	***2.8***	***3.7***	***4.3***	
Hypospadias*	754	36	134	28	9	994	
	94.2	***154.2***	***59.0***	***51.6***	***63.5***	***85.0***	
Limb deficiencies (reduction defects)	117	3	35	3	3	174	
	7.5	***6.5***	***7.8***	***2.8***	***11.0***	***7.6***	
Spina bifida without anencephalus	133	4	46	7	3	198	
	8.5	***8.6***	***10.3***	***6.6***	***11.0***	***8.7***	
Tetralogy of Fallot	98	2	31	4	1	143	
	6.3	***4.3***	***6.9***	***3.8***	***3.7***	***6.3***	
Transposition of the great arteries (TGA)	108	1	27	6	3	155	
	6.9	***2.2***	***6.1***	***5.7***	***11.0***	***6.8***	
Trisomy 21 (Down syndrome)	270	10	114	19	7	431	
	17.3	***21.5***	***25.6***	***17.9***	***25.6***	***18.9***	
Total live births	**155778**	**4650**	**44612**	**10600**	**2738**	**228115**	
Male live births	**80038**	**2335**	**22723**	**5423**	**1418**	**116950**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

Oregon

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	110	4	114	
	5.7	***1.1***	***5.0***	
Trisomy 21 (Down syndrome)	248	183	431	
	12.9	***51.7***	***18.9***	
Total live births	**192704**	**35406**	**228115**	

**Total includes unknown maternal age

Puerto Rico

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity		
Defect	**Hispanic**	**Total****	**Notes**
Anencephalus	77 ***3.8***	77 ***3.8***	
Anophthalmia/microphthalmia	32 ***1.6***	32 ***1.6***	
Anotia/microtia	47 ***2.3***	47 ***2.3***	
Aortic valve stenosis	22 ***1.1***	22 ***1.1***	
Atrial septal defect	506 ***24.8***	506 ***24.8***	
Atrioventricular septal defect (Endocardial cushion defect)	96 ***4.7***	96 ***4.7***	1
Bladder exstrophy	3 ***0.1***	3 ***0.1***	
Cleft lip alone	73 ***3.6***	73 ***3.6***	
Cleft lip with cleft palate	130 ***6.4***	130 ***6.4***	
Cleft palate alone	129 ***6.3***	129 ***6.3***	
Clubfoot	351 ***17.2***	351 ***17.2***	
Coarctation of the aorta	61 ***3.0***	61 ***3.0***	
Common truncus (truncus arteriosus)	11 ***0.5***	11 ***0.5***	
Double outlet right ventricle	35 ***1.7***	35 ***1.7***	
Ebstein anomaly	21 ***1.0***	21 ***1.0***	
Encephalocele	24 ***1.2***	24 ***1.2***	
Gastroschisis	99 ***4.9***	99 ***4.9***	
Hypoplastic left heart syndrome	41 ***2.0***	41 ***2.0***	
Hypospadias*	440 ***41.9***	440 ***41.9***	
Limb deficiencies (reduction defects)	147 ***7.2***	147 ***7.2***	
Omphalocele	38 ***1.9***	38 ***1.9***	
Pulmonary valve atresia and stenosis	191 ***9.4***	191 ***9.4***	
Pulmonary valve atresia	21 ***1.0***	21 ***1.0***	
Spina bifida without anencephalus	106 ***5.2***	106 ***5.2***	
Tetralogy of Fallot	82 ***4.0***	82 ***4.0***	
Total anomalous pulmonary venous connection	14 ***0.7***	14 ***0.7***	
Transposition of the great arteries (TGA)	54 ***2.7***	54 ***2.7***	
Dextro-transposition of great arteries (d-TGA)	54 ***2.7***	54 ***2.7***	
Tricuspid valve atresia and stenosis	16 ***0.8***	16 ***0.8***	
Tricuspid valve atresia	19 ***0.9***	19 ***0.9***	
Trisomy 13	33 ***1.6***	33 ***1.6***	
Trisomy 18	82 ***4.0***	82 ***4.0***	

Puerto Rico

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity		
Defect	**Hispanic**	**Total****	**Notes**
Trisomy 21 (Down syndrome)	268	268	
	13.2	***13.2***	
Ventricular septal defect	529	529	2
	26.0	***26.0***	
Total live births	**203719**	**203719**	
Male live births	**104909**	**104909**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

Puerto Rico

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	98	0	99	
	5.3	***0.0***	***4.9***	
Trisomy 13	23	10	33	
	1.2	***5.7***	***1.6***	
Trisomy 18	52	30	82	
	2.8	***17.1***	***4.0***	
Trisomy 21 (Down syndrome)	160	108	268	
	8.6	***61.5***	***13.2***	
Total live births	**186089**	**17566**	**203719**	

**Total includes unknown maternal age

Notes
1.Data for this condition only include atrioventricular canal.
2.Data for this condition exclude probable diagnosis and exclude inlet/posterior type ventricular septal defect only in the presence of atrioventricular canal.

General comments
-Fetal deaths include includes spontaneous abortions and stillbirths.
-There is no gestational age cut off for terminations.

Rhode Island

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	9	1	1	0	0	11	
	2.7	***2.1***	***0.8***	***0.0***	***0.0***	***2.0***	
Anophthalmia/microphthalmia	2	1	1	0	0	5	
	0.6	***2.1***	***0.8***	***0.0***	***0.0***	***0.9***	
Anotia/microtia	1	1	0	0	0	2	
	0.3	***2.1***	***0.0***	***0.0***	***0.0***	***0.4***	
Aortic valve stenosis	8	0	2	0	0	10	
	2.4	***0.0***	***1.6***	***0.0***	***0.0***	***1.9***	
Atrial septal defect	88	20	25	3	2	147	
	26.5	***42.2***	***19.9***	***11.8***	***46.4***	***27.3***	
Atrioventricular septal defect (Endocardial cushion defect)	10	0	1	0	0	11	
	3.0	***0.0***	***0.8***	***0.0***	***0.0***	***2.0***	
Biliary atresia	1	0	1	0	0	3	
	0.3	***0.0***	***0.8***	***0.0***	***0.0***	***0.6***	
Bladder exstrophy	0	1	0	0	0	1	
	0.0	***2.1***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	1	1	0	0	0	2	
	0.3	***2.1***	***0.0***	***0.0***	***0.0***	***0.4***	
Cleft lip alone	13	0	4	0	0	18	
	3.9	***0.0***	***3.2***	***0.0***	***0.0***	***3.3***	
Cleft lip with cleft palate	16	0	9	1	1	28	
	4.8	***0.0***	***7.2***	***3.9***	***23.2***	***5.2***	
Cleft palate alone	15	1	2	3	0	22	
	4.5	***2.1***	***1.6***	***11.8***	***0.0***	***4.1***	
Cloacal exstrophy	0	0	0	0	0	1	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Clubfoot	50	8	16	3	0	79	
	15.1	***16.9***	***12.7***	***11.8***	***0.0***	***14.7***	
Coarctation of the aorta	9	3	2	1	0	15	
	2.7	***6.3***	***1.6***	***3.9***	***0.0***	***2.8***	
Common truncus (truncus arteriosus)	1	1	0	0	0	2	
	0.3	***2.1***	***0.0***	***0.0***	***0.0***	***0.4***	
Congenital cataract	1	1	2	0	0	4	
	0.3	***2.1***	***1.6***	***0.0***	***0.0***	***0.7***	
Congenital posterior urethral valves	2	1	1	0	0	4	
	0.6	***2.1***	***0.8***	***0.0***	***0.0***	***0.7***	
Craniosynostosis	20	0	6	3	0	30	
	6.0	***0.0***	***4.8***	***11.8***	***0.0***	***5.6***	
Deletion 22q11.2	1	0	0	0	0	1	
	0.3	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Diaphragmatic hernia	9	1	3	0	0	13	
	2.7	***2.1***	***2.4***	***0.0***	***0.0***	***2.4***	
Double outlet right ventricle	2	2	0	2	0	6	
	0.6	***4.2***	***0.0***	***7.9***	***0.0***	***1.1***	
Ebstein anomaly	3	1	1	0	0	5	
	0.9	***2.1***	***0.8***	***0.0***	***0.0***	***0.9***	
Encephalocele	3	0	3	0	0	7	
	0.9	***0.0***	***2.4***	***0.0***	***0.0***	***1.3***	
Esophageal atresia/tracheoesophageal fistula	7	0	1	0	0	8	
	2.1	***0.0***	***0.8***	***0.0***	***0.0***	***1.5***	
Gastroschisis	10	1	12	0	0	24	
	3.0	***2.1***	***9.5***	***0.0***	***0.0***	***4.5***	
Holoprosencephaly	2	1	1	0	0	5	
	0.6	***2.1***	***0.8***	***0.0***	***0.0***	***0.9***	
Hypoplastic left heart syndrome	7	4	4	1	0	16	
	2.1	***8.4***	***3.2***	***3.9***	***0.0***	***3.0***	
Hypospadias*	175	17	33	6	1	237	
	103.4	***69.4***	***51.2***	***45.8***	***45.5***	***86.0***	
Interrupted aortic arch	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	

Rhode Island

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	12	2	5	0	0	19	
	3.6	***4.2***	***4.0***	***0.0***	***0.0***	***3.5***	
Omphalocele	9	1	4	1	0	15	
	2.7	***2.1***	***3.2***	***3.9***	***0.0***	***2.8***	
Pulmonary valve atresia and stenosis	15	2	13	4	0	36	
	4.5	***4.2***	***10.3***	***15.7***	***0.0***	***6.7***	
Pulmonary valve atresia	2	0	3	3	0	8	
	0.6	***0.0***	***2.4***	***11.8***	***0.0***	***1.5***	
Rectal and large intestinal atresia/stenosis	10	3	6	0	0	20	
	3.0	***6.3***	***4.8***	***0.0***	***0.0***	***3.7***	
Renal agenesis/hypoplasia	8	2	5	0	0	16	
	2.4	***4.2***	***4.0***	***0.0***	***0.0***	***3.0***	
Single ventricle	0	0	0	0	0	1	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Small intestinal atresia/stenosis	15	5	8	2	0	31	
	4.5	***10.6***	***6.4***	***7.9***	***0.0***	***5.8***	
Spina bifida without anencephalus	14	3	5	0	0	26	
	4.2	***6.3***	***4.0***	***0.0***	***0.0***	***4.8***	
Tetralogy of Fallot	6	3	3	1	0	13	
	1.8	***6.3***	***2.4***	***3.9***	***0.0***	***2.4***	
Total anomalous pulmonary venous connection	3	0	0	0	0	4	
	0.9	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Transposition of the great arteries (TGA)	3	0	2	1	0	9	
	0.9	***0.0***	***1.6***	***3.9***	***0.0***	***1.7***	
Dextro-transposition of great arteries (d-TGA)	2	2	0	2	0	6	
	0.6	***4.2***	***0.0***	***7.9***	***0.0***	***1.1***	
Tricuspid valve atresia and stenosis	1	0	2	1	0	4	
	0.3	***0.0***	***1.6***	***3.9***	***0.0***	***0.7***	
Tricuspid valve atresia	1	0	2	1	0	4	
	0.3	***0.0***	***1.6***	***3.9***	***0.0***	***0.7***	
Trisomy 13	6	3	3	0	0	13	
	1.8	***6.3***	***2.4***	***0.0***	***0.0***	***2.4***	
Trisomy 18	10	3	4	0	0	20	
	3.0	***6.3***	***3.2***	***0.0***	***0.0***	***3.7***	
Trisomy 21 (Down syndrome)	53	9	14	1	1	93	
	16.0	***19.0***	***11.1***	***3.9***	***23.2***	***17.3***	
Turner syndrome†	3	0	1	1	0	5	
	1.8	***0.0***	***1.6***	***8.1***	***0.0***	***1.9***	
Ventricular septal defect	146	31	41	10	2	237	1
	44.0	***65.5***	***32.6***	***39.3***	***46.4***	***44.0***	
Total live births §	**33157**	**4735**	**12584**	**2544**	**431**	**53843**	
Male live births	**16928**	**2451**	**6442**	**1309**	**220**	**27560**	
Female live births	**16229**	**2283**	**6142**	**1235**	**211**	**26282**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Rhode Island

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	23	1	24	
	5.1	***1.1***	***4.5***	
Trisomy 13	7	5	13	
	1.6	***5.5***	***2.4***	
Trisomy 18	7	11	20	
	1.6	***12.1***	***3.7***	
Trisomy 21 (Down syndrome)	39	45	93	
	8.7	***49.4***	***17.3***	
Total live births	**44738**	**9103**	**53843**	

**Total includes unknown maternal age

Notes
1.Data for this condition include probable cases.

General comments
-Stillbirths are fetal deaths at 20 weeks or more gestation.
-Terminations are induced fetal deaths at 20 weeks or more gestation.

South Carolina

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	43	13	13	0	0	71	
	2.6	***1.4***	***5.3***	***0.0***	***0.0***	***2.4***	
Anophthalmia/microphthalmia	14	8	1	0	0	23	
	0.8	***0.9***	***0.4***	***0.0***	***0.0***	***0.8***	
Anotia/microtia	13	10	1	1	0	25	
	0.8	***1.1***	***0.4***	***1.9***	***0.0***	***0.9***	
Aortic valve stenosis	15	9	3	0	0	27	
	0.9	***1.0***	***1.2***	***0.0***	***0.0***	***0.9***	
Atrioventricular septal defect (Endocardial cushion defect)	96	51	13	1	0	163	
	5.7	***5.4***	***5.3***	***1.9***	***0.0***	***5.6***	
Biliary atresia	6	9	1	0	0	16	
	0.4	***1.0***	***0.4***	***0.0***	***0.0***	***0.5***	
Bladder exstrophy	4	1	0	0	0	5	1
	0.2	***0.1***	***0.0***	***0.0***	***0.0***	***0.2***	
Choanal atresia	21	9	1	0	0	33	
	1.3	***1.0***	***0.4***	***0.0***	***0.0***	***1.1***	
Cleft palate alone	89	34	12	5	0	142	
	5.3	***3.6***	***4.9***	***9.6***	***0.0***	***4.9***	
Coarctation of the aorta	110	46	12	3	1	174	
	6.6	***4.9***	***4.9***	***5.8***	***8.3***	***5.9***	
Common truncus (truncus arteriosus)	11	3	1	0	1	16	
	0.7	***0.3***	***0.4***	***0.0***	***8.3***	***0.5***	
Congenital cataract	11	6	4	0	0	21	
	0.7	***0.6***	***1.6***	***0.0***	***0.0***	***0.7***	
Diaphragmatic hernia	50	27	9	0	0	89	
	3.0	***2.9***	***3.7***	***0.0***	***0.0***	***3.0***	
Double outlet right ventricle	42	35	4	0	0	83	
	2.5	***3.7***	***1.6***	***0.0***	***0.0***	***2.8***	
Ebstein anomaly	12	5	3	0	0	20	
	0.7	***0.5***	***1.2***	***0.0***	***0.0***	***0.7***	
Encephalocele	16	10	6	1	0	33	
	1.0	***1.1***	***2.4***	***1.9***	***0.0***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	34	12	3	1	0	51	
	2.0	***1.3***	***1.2***	***1.9***	***0.0***	***1.7***	
Gastroschisis	81	24	11	1	0	119	
	4.8	***2.6***	***4.5***	***1.9***	***0.0***	***4.1***	
Hypoplastic left heart syndrome	65	48	8	1	0	123	
	3.9	***5.1***	***3.3***	***1.9***	***0.0***	***4.2***	
Limb deficiencies (reduction defects)	107	61	14	8	1	192	
	6.4	***6.5***	***5.7***	***15.4***	***8.3***	***6.6***	
Omphalocele	39	23	3	0	1	68	
	2.3	***2.5***	***1.2***	***0.0***	***8.3***	***2.3***	
Pulmonary valve atresia and stenosis	134	105	20	4	1	269	
	8.0	***11.2***	***8.1***	***7.7***	***8.3***	***9.2***	
Rectal and large intestinal atresia/stenosis	77	36	2	4	0	120	
	4.6	***3.8***	***0.8***	***7.7***	***0.0***	***4.1***	
Renal agenesis/hypoplasia	85	50	11	4	0	150	
	5.1	***5.3***	***4.5***	***7.7***	***0.0***	***5.1***	
Spina bifida without anencephalus	60	23	6	4	0	97	
	3.6	***2.5***	***2.4***	***7.7***	***0.0***	***3.3***	
Tetralogy of Fallot	84	52	11	1	0	150	
	5.0	***5.6***	***4.5***	***1.9***	***0.0***	***5.1***	
Transposition of the great arteries (TGA)	45	31	5	1	0	84	
	2.7	***3.3***	***2.0***	***1.9***	***0.0***	***2.9***	
Tricuspid valve atresia and stenosis	18	14	0	1	0	34	
	1.1	***1.5***	***0.0***	***1.9***	***0.0***	***1.2***	
Trisomy 13	13	12	6	1	0	32	
	0.8	***1.3***	***2.4***	***1.9***	***0.0***	***1.1***	
Trisomy 18	46	24	9	0	0	79	
	2.7	***2.6***	***3.7***	***0.0***	***0.0***	***2.7***	

South Carolina

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Trisomy 21 (Down syndrome)	200	73	42	6	0	328	
	11.9	***7.8***	***17.1***	***11.5***	***0.0***	***11.2***	
Ventricular septal defect	636	333	139	19	1	1144	2
	37.9	***35.6***	***56.5***	***36.5***	***8.3***	***39.1***	
Total live births	**167687**	**93632**	**24588**	**5206**	**1199**	**292526**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

South Carolina

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	114	5	119	
	4.4	***1.5***	***4.1***	
Trisomy 13	23	9	32	
	0.9	***2.8***	***1.1***	
Trisomy 18	41	38	79	
	1.6	***11.7***	***2.7***	
Trisomy 21 (Down syndrome)	177	151	328	
	6.8	***46.3***	***11.2***	
Total live births	**259926**	**32583**	**292526**	

**Total includes unknown maternal age

Notes
1.Data for this condition begin in 2010.
2.Data for this condition include confirmed cases only.

General comments
-Abortions in South Carolina are not usually performed after 24 weeks gestation.
-Fetal Deaths include those that occur in a hospital at 20 weeks or more gestation.

Tennessee

Birth Defects Counts and Prevalence 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	34	8	8	1	0	51	
	1.6	***1.2***	***2.8***	***1.5***	***0.0***	***1.6***	
Anophthalmia/microphthalmia	26	12	3	1	0	43	
	1.2	***1.8***	***1.1***	***1.5***	***0.0***	***1.3***	
Anotia/microtia	17	4	7	2	0	30	
	0.8	***0.6***	***2.5***	***2.9***	***0.0***	***0.9***	
Aortic valve stenosis	51	11	7	0	0	69	
	2.4	***1.7***	***2.5***	***0.0***	***0.0***	***2.1***	
Atrial septal defect	2727	1363	323	54	1	4480	
	126.5	***204.7***	***113.2***	***78.5***	***21.0***	***139.5***	
Atrioventricular septal defect (Endocardial cushion defect)	109	42	14	3	1	170	1
	5.1	***6.3***	***4.9***	***4.4***	***21.0***	***5.3***	
Biliary atresia	22	8	4	0	0	35	
	1.0	***1.2***	***1.4***	***0.0***	***0.0***	***1.1***	
Bladder exstrophy	9	2	1	0	0	12	
	0.4	***0.3***	***0.4***	***0.0***	***0.0***	***0.4***	
Choanal atresia	49	6	6	1	0	62	
	2.3	***0.9***	***2.1***	***1.5***	***0.0***	***1.9***	
Cleft palate alone	211	41	21	4	1	278	
	9.8	***6.2***	***7.4***	***5.8***	***21.0***	***8.7***	
Coarctation of the aorta	177	46	24	2	0	251	
	8.2	***6.9***	***8.4***	***2.9***	***0.0***	***7.8***	
Common truncus (truncus arteriosus)	24	9	2	1	0	36	
	1.1	***1.4***	***0.7***	***1.5***	***0.0***	***1.1***	
Congenital cataract	43	16	3	3	0	65	
	2.0	***2.4***	***1.1***	***4.4***	***0.0***	***2.0***	
Diaphragmatic hernia	93	37	13	1	0	144	
	4.3	***5.6***	***4.6***	***1.5***	***0.0***	***4.5***	
Ebstein anomaly	30	10	6	2	0	48	
	1.4	***1.5***	***2.1***	***2.9***	***0.0***	***1.5***	
Encephalocele	27	9	8	0	0	44	
	1.3	***1.4***	***2.8***	***0.0***	***0.0***	***1.4***	
Esophageal atresia/tracheoesophageal fistula	79	15	12	0	0	106	
	3.7	***2.3***	***4.2***	***0.0***	***0.0***	***3.3***	
Gastroschisis	147	22	15	0	0	187	
	6.8	***3.3***	***5.3***	***0.0***	***0.0***	***5.8***	
Hypoplastic left heart syndrome	80	27	15	1	1	125	
	3.7	***4.1***	***5.3***	***1.5***	***21.0***	***3.9***	
Hypospadias*	1298	360	59	22	3	1752	
	117.3	***105.8***	***40.5***	***62.4***	***127.7***	***106.5***	
Omphalocele	61	15	5	0	0	81	
	2.8	***2.3***	***1.8***	***0.0***	***0.0***	***2.5***	
Pulmonary valve atresia and stenosis	200	65	29	5	1	300	
	9.3	***9.8***	***10.2***	***7.3***	***21.0***	***9.3***	
Pulmonary valve atresia	38	16	7	2	0	63	
	1.8	***2.4***	***2.5***	***2.9***	***0.0***	***2.0***	
Rectal and large intestinal atresia/stenosis	146	41	11	1	1	200	
	6.8	***6.2***	***3.9***	***1.5***	***21.0***	***6.2***	
Renal agenesis/hypoplasia	130	44	14	2	0	190	
	6.0	***6.6***	***4.9***	***2.9***	***0.0***	***5.9***	
Spina bifida without anencephalus	95	20	16	4	0	135	
	4.4	***3.0***	***5.6***	***5.8***	***0.0***	***4.2***	
Tetralogy of Fallot	137	45	13	1	0	196	
	6.4	***6.8***	***4.6***	***1.5***	***0.0***	***6.1***	
Transposition of the great arteries (TGA)	108	42	18	5	0	175	
	5.0	***6.3***	***6.3***	***7.3***	***0.0***	***5.4***	
Dextro-transposition of great arteries (d-TGA)	64	18	9	4	0	95	
	3.0	***2.7***	***3.2***	***5.8***	***0.0***	***3.0***	
Tricuspid valve atresia and stenosis	34	9	3	0	0	46	2
	1.6	***1.4***	***1.1***	***0.0***	***0.0***	***1.4***	

Tennessee

Birth Defects Counts and Prevalence 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Trisomy 13	16	8	0	0	0	26	
	0.7	***1.2***	***0.0***	***0.0***	***0.0***	***0.8***	
Trisomy 18	38	13	6	1	0	59	
	1.8	***2.0***	***2.1***	***1.5***	***0.0***	***1.8***	
Trisomy 21 (Down syndrome)	301	93	50	9	1	456	
	14.0	***14.0***	***17.5***	***13.1***	***21.0***	***14.2***	
Ventricular septal defect	1118	349	162	29	3	1667	3
	51.9	***52.4***	***56.8***	***42.2***	***62.9***	***51.9***	
Total live births	**215597**	**66592**	**28538**	**6877**	**477**	**321118**	
Male live births	**110664**	**34031**	**14579**	**3528**	**235**	**164532**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

Tennessee

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2012 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	186	1	187	
	6.5	***0.3***	***5.8***	
Trisomy 13	20	6	26	
	0.7	***1.8***	***0.8***	
Trisomy 18	42	17	59	
	1.5	***5.0***	***1.8***	
Trisomy 21 (Down syndrome)	278	178	456	
	9.7	***52.7***	***14.2***	
Total live births	**287223**	**33782**	**321118**	

**Total includes unknown maternal age

Notes
1.Data for this condition includes inlet ventricular septal defect.
2.Data for this condition includes stenosis or hypoplasia.
3.Data for this condition includes inlet ventricular septal defect and probable cases.

General comments
-Fetal deaths are defined as 500 grams or more, or 22 weeks gestation or more.

Texas

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	159	32	315	7	3	527	
	2.4	***1.5***	***3.3***	***0.8***	***8.3***	***2.7***	
Anophthalmia/microphthalmia	181	46	325	19	0	577	
	2.7	***2.1***	***3.5***	***2.3***	***0.0***	***3.0***	
Anotia/microtia	150	27	473	18	2	673	
	2.2	***1.2***	***5.0***	***2.2***	***5.6***	***3.5***	
Aortic valve stenosis	169	31	282	11	2	496	
	2.5	***1.4***	***3.0***	***1.3***	***5.6***	***2.6***	
Atrial septal defect	5088	1856	7687	540	26	15330	
	76.3	***84.2***	***81.7***	***64.8***	***72.3***	***79.3***	
Atrioventricular septal defect (Endocardial cushion defect)	330	102	389	30	1	857	
	4.9	***4.6***	***4.1***	***3.6***	***2.8***	***4.4***	
Biliary atresia	40	12	67	14	1	136	
	0.6	***0.5***	***0.7***	***1.7***	***2.8***	***0.7***	
Bladder exstrophy	19	7	10	1	0	37	
	0.3	***0.3***	***0.1***	***0.1***	***0.0***	***0.2***	
Choanal atresia	115	29	106	6	0	258	
	1.7	***1.3***	***1.1***	***0.7***	***0.0***	***1.3***	
Cleft lip alone	256	55	259	26	1	602	
	3.8	***2.5***	***2.8***	***3.1***	***2.8***	***3.1***	
Cleft lip with cleft palate	440	92	795	57	9	1405	
	6.6	***4.2***	***8.5***	***6.8***	***25.0***	***7.3***	
Cleft palate alone	415	98	563	66	4	1160	
	6.2	***4.4***	***6.0***	***7.9***	***11.1***	***6.0***	
Cloacal exstrophy	4	0	8	0	0	12	
	0.1	***0.0***	***0.1***	***0.0***	***0.0***	***0.1***	
Clubfoot	1131	363	1579	79	11	3192	
	17.0	***16.5***	***16.8***	***9.5***	***30.6***	***16.5***	
Coarctation of the aorta	379	106	522	36	4	1056	
	5.7	***4.8***	***5.5***	***4.3***	***11.1***	***5.5***	
Common truncus (truncus arteriosus)	48	18	93	4	0	164	
	0.7	***0.8***	***1.0***	***0.5***	***0.0***	***0.8***	
Congenital cataract	119	45	186	10	0	361	
	1.8	***2.0***	***2.0***	***1.2***	***0.0***	***1.9***	
Congenital posterior urethral valves	66	39	55	16	0	176	
	1.0	***1.8***	***0.6***	***1.9***	***0.0***	***0.9***	
Craniosynostosis	510	64	580	28	2	1192	
	7.6	***2.9***	***6.2***	***3.4***	***5.6***	***6.2***	
Deletion 22q11.2	50	19	86	5	2	163	
	0.7	***0.9***	***0.9***	***0.6***	***5.6***	***0.8***	
Diaphragmatic hernia	193	54	279	19	1	546	
	2.9	***2.5***	***3.0***	***2.3***	***2.8***	***2.8***	
Double outlet right ventricle	132	40	277	16	1	469	
	2.0	***1.8***	***2.9***	***1.9***	***2.8***	***2.4***	
Ebstein anomaly	50	7	80	3	0	141	
	0.7	***0.3***	***0.9***	***0.4***	***0.0***	***0.7***	
Encephalocele	51	29	108	12	0	205	
	0.8	***1.3***	***1.1***	***1.4***	***0.0***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	183	42	201	14	1	442	
	2.7	***1.9***	***2.1***	***1.7***	***2.8***	***2.3***	
Gastroschisis	370	99	652	25	2	1155	
	5.5	***4.5***	***6.9***	***3.0***	***5.6***	***6.0***	
Holoprosencephaly	51	18	105	4	0	180	
	0.8	***0.8***	***1.1***	***0.5***	***0.0***	***0.9***	
Hypoplastic left heart syndrome	181	57	203	12	1	458	
	2.7	***2.6***	***2.2***	***1.4***	***2.8***	***2.4***	
Hypospadias*	3004	832	2141	269	8	6317	
	87.8	***74.1***	***44.7***	***62.2***	***43.7***	***63.9***	
Interrupted aortic arch	43	14	53	2	0	112	
	0.6	***0.6***	***0.6***	***0.2***	***0.0***	***0.6***	

Texas

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	374	147	568	22	4	1125	
	5.6	***6.7***	***6.0***	***2.6***	***11.1***	***5.8***	
Omphalocele	157	53	179	17	0	407	
	2.4	***2.4***	***1.9***	***2.0***	***0.0***	***2.1***	
Pulmonary valve atresia and stenosis	646	242	1167	56	5	2134	
	9.7	***11.0***	***12.4***	***6.7***	***13.9***	***11.0***	
Pulmonary valve atresia	65	23	100	8	0	200	
	1.0	***1.0***	***1.1***	***1.0***	***0.0***	***1.0***	
Rectal and large intestinal atresia/stenosis	324	104	551	33	4	1030	
	4.9	***4.7***	***5.9***	***4.0***	***11.1***	***5.3***	
Renal agenesis/hypoplasia	428	160	623	60	3	1293	
	6.4	***7.3***	***6.6***	***7.2***	***8.3***	***6.7***	
Single ventricle	45	15	86	5	0	151	
	0.7	***0.7***	***0.9***	***0.6***	***0.0***	***0.8***	
Small intestinal atresia/stenosis	224	74	342	18	1	661	
	3.4	***3.4***	***3.6***	***2.2***	***2.8***	***3.4***	
Spina bifida without anencephalus	247	61	436	14	1	769	
	3.7	***2.8***	***4.6***	***1.7***	***2.8***	***4.0***	
Tetralogy of Fallot	309	112	422	39	3	900	
	4.6	***5.1***	***4.5***	***4.7***	***8.3***	***4.7***	
Total anomalous pulmonary venous connection	81	22	205	19	0	329	
	1.2	***1.0***	***2.2***	***2.3***	***0.0***	***1.7***	
Transposition of the great arteries (TGA)	262	56	343	25	0	690	
	3.9	***2.5***	***3.6***	***3.0***	***0.0***	***3.6***	
Dextro-transposition of great arteries (d-TGA)	226	48	299	22	0	598	
	3.4	***2.2***	***3.2***	***2.6***	***0.0***	***3.1***	
Tricuspid valve atresia and stenosis	131	53	183	15	1	385	
	2.0	***2.4***	***1.9***	***1.8***	***2.8***	***2.0***	
Tricuspid valve atresia	56	24	64	7	0	151	
	0.8	***1.1***	***0.7***	***0.8***	***0.0***	***0.8***	
Trisomy 13	91	28	110	15	0	248	
	1.4	***1.3***	***1.2***	***1.8***	***0.0***	***1.3***	
Trisomy 18	183	56	255	28	0	530	
	2.7	***2.5***	***2.7***	***3.4***	***0.0***	***2.7***	
Trisomy 21 (Down syndrome)	872	229	1570	97	4	2802	
	13.1	***10.4***	***16.7***	***11.6***	***11.1***	***14.5***	
Turner syndrome†	103	20	128	10	0	263	
	3.2	***1.8***	***2.8***	***2.5***	***0.0***	***2.8***	
Ventricular septal defect	3933	1169	7155	472	30	12859	1
	58.9	***53.1***	***76.1***	***56.6***	***83.4***	***66.5***	
Total live births	**667219**	**220352**	**940681**	**83368**	**3596**	**1934167**	
Male live births	**342038**	**112219**	**479127**	**43267**	**1832**	**988179**	
Female live births	**325181**	**108133**	**461554**	**40101**	**1764**	**945988**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

Texas

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	1136	19	1155	
	6.7	***0.8***	***6.0***	
Trisomy 13	175	73	248	
	1.0	***3.0***	***1.3***	
Trisomy 18	272	258	530	
	1.6	***10.5***	***2.7***	
Trisomy 21 (Down syndrome)	1472	1330	2802	
	8.7	***54.3***	***14.5***	
Total live births	**1689334**	**244749**	**1934167**	

**Total includes unknown maternal age

Notes
1.Data for this condition include inlet ventricular septal defect.

General comments
-Data for all conditions exclude possible/probable cases.
-Fetal death defined as spontaneous death of a conception product prior to the complete expulsion/extraction from its mother, regardless of gestational length. The labor onset may be natural/induced, but not a result of an intended procedure.

Utah

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	47	2	15	1	1	67	
	2.3	***7.4***	***3.8***	***1.1***	***3.5***	***2.6***	
Anophthalmia/microphthalmia	4	1	4	0	0	9	
	0.2	***3.7***	***1.0***	***0.0***	***0.0***	***0.3***	
Anotia/microtia	61	2	28	10	1	102	
	3.0	***7.4***	***7.0***	***11.2***	***3.5***	***3.9***	
Aortic valve stenosis	62	0	15	4	1	82	
	3.1	***0.0***	***3.8***	***4.5***	***3.5***	***3.2***	
Atrial septal defect	845	13	185	50	12	1108	
	41.7	***48.1***	***46.6***	***56.0***	***42.1***	***42.7***	
Atrioventricular septal defect (Endocardial cushion defect)	148	4	22	13	1	188	
	7.3	***14.8***	***5.5***	***14.6***	***3.5***	***7.2***	
Biliary atresia	14	0	2	1	0	17	
	0.7	***0.0***	***0.5***	***1.1***	***0.0***	***0.7***	
Bladder exstrophy	4	0	0	1	0	5	
	0.2	***0.0***	***0.0***	***1.1***	***0.0***	***0.2***	
Choanal atresia	33	0	4	0	0	37	
	1.6	***0.0***	***1.0***	***0.0***	***0.0***	***1.4***	
Cleft lip alone	118	3	13	4	1	142	
	5.8	***11.1***	***3.3***	***4.5***	***3.5***	***5.5***	
Cleft lip with cleft palate	163	3	39	2	3	211	
	8.0	***11.1***	***9.8***	***2.2***	***10.5***	***8.1***	
Cleft palate alone	121	2	14	10	4	152	
	6.0	***7.4***	***3.5***	***11.2***	***14.0***	***5.9***	
Cloacal exstrophy	9	0	0	1	0	10	
	0.4	***0.0***	***0.0***	***1.1***	***0.0***	***0.4***	
Clubfoot	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Coarctation of the aorta	206	2	28	5	4	246	
	10.2	***7.4***	***7.0***	***5.6***	***14.0***	***9.5***	
Common truncus (truncus arteriosus)	16	1	2	1	0	20	
	0.8	***3.7***	***0.5***	***1.1***	***0.0***	***0.8***	
Congenital cataract	59	0	12	3	1	75	
	2.9	***0.0***	***3.0***	***3.4***	***3.5***	***2.9***	
Congenital posterior urethral valves	29	0	5	1	0	35	1
	1.4	***0.0***	***1.3***	***1.1***	***0.0***	***1.3***	
Craniosynostosis	223	3	45	5	4	281	
	11.0	***11.1***	***11.3***	***5.6***	***14.0***	***10.8***	
Deletion 22q11.2	21	1	3	6	3	34	
	1.0	***3.7***	***0.8***	***6.7***	***10.5***	***1.3***	
Diaphragmatic hernia	35	1	6	2	2	46	
	1.7	***3.7***	***1.5***	***2.2***	***7.0***	***1.8***	
Double outlet right ventricle	41	0	5	2	1	49	
	2.0	***0.0***	***1.3***	***2.2***	***3.5***	***1.9***	
Ebstein anomaly	21	0	5	1	0	27	
	1.0	***0.0***	***1.3***	***1.1***	***0.0***	***1.0***	
Encephalocele	20	0	3	0	0	23	
	1.0	***0.0***	***0.8***	***0.0***	***0.0***	***0.9***	
Esophageal atresia/tracheoesophageal fistula	54	0	9	3	2	69	
	2.7	***0.0***	***2.3***	***3.4***	***7.0***	***2.7***	
Gastroschisis	77	0	19	4	1	102	
	3.8	***0.0***	***4.8***	***4.5***	***3.5***	***3.9***	
Holoprosencephaly	27	2	7	0	0	36	
	1.3	***7.4***	***1.8***	***0.0***	***0.0***	***1.4***	
Hypoplastic left heart syndrome	64	2	8	4	1	79	
	3.2	***7.4***	***2.0***	***4.5***	***3.5***	***3.0***	
Hypospadias*	811	7	51	24	7	902	
	77.7	***50.0***	***25.3***	***52.0***	***48.7***	***67.6***	
Interrupted aortic arch	9	1	4	3	1	18	
	0.4	***3.7***	***1.0***	***3.4***	***3.5***	***0.7***	

Utah

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Limb deficiencies (reduction defects)	125	4	26	2	1	160	
	6.2	***14.8***	***6.5***	***2.2***	***3.5***	***6.2***	
Omphalocele	62	1	17	1	3	84	
	3.1	***3.7***	***4.3***	***1.1***	***10.5***	***3.2***	
Pulmonary valve atresia and stenosis	285	5	57	17	4	370	
	14.1	***18.5***	***14.3***	***19.0***	***14.0***	***14.3***	
Pulmonary valve atresia	17	0	4	2	0	23	
	0.8	***0.0***	***1.0***	***2.2***	***0.0***	***0.9***	
Rectal and large intestinal atresia/stenosis	77	1	9	9	0	97	
	3.8	***3.7***	***2.3***	***10.1***	***0.0***	***3.7***	
Renal agenesis/hypoplasia	74	0	13	5	3	96	
	3.7	***0.0***	***3.3***	***5.6***	***10.5***	***3.7***	
Single ventricle	10	0	3	0	0	13	
	0.5	***0.0***	***0.8***	***0.0***	***0.0***	***0.5***	
Small intestinal atresia/stenosis	29	0	5	4	0	38	
	1.4	***0.0***	***1.3***	***4.5***	***0.0***	***1.5***	
Spina bifida without anencephalus	66	2	13	3	2	86	
	3.3	***7.4***	***3.3***	***3.4***	***7.0***	***3.3***	
Tetralogy of Fallot	62	1	9	5	3	81	
	3.1	***3.7***	***2.3***	***5.6***	***10.5***	***3.1***	
Total anomalous pulmonary venous connection	19	0	8	0	1	28	
	0.9	***0.0***	***2.0***	***0.0***	***3.5***	***1.1***	
Transposition of the great arteries (TGA)	105	1	18	4	1	130	
	5.2	***3.7***	***4.5***	***4.5***	***3.5***	***5.0***	
Dextro-transposition of great arteries (d-TGA)	50	1	8	3	0	62	
	2.5	***3.7***	***2.0***	***3.4***	***0.0***	***2.4***	
Tricuspid valve atresia and stenosis	26	1	7	0	0	34	
	1.3	***3.7***	***1.8***	***0.0***	***0.0***	***1.3***	
Tricuspid valve atresia	26	1	7	0	0	34	
	1.3	***3.7***	***1.8***	***0.0***	***0.0***	***1.3***	
Trisomy 13	31	1	9	2	0	43	
	1.5	***3.7***	***2.3***	***2.2***	***0.0***	***1.7***	
Trisomy 18	71	1	14	2	2	93	
	3.5	***3.7***	***3.5***	***2.2***	***7.0***	***3.6***	
Trisomy 21 (Down syndrome)	301	4	79	22	5	417	
	14.8	***14.8***	***19.9***	***24.6***	***17.5***	***16.1***	
Turner syndrome†	44	0	12	0	1	58	
	4.5	***0.0***	***6.1***	***0.0***	***7.1***	***4.6***	
Ventricular septal defect	486	8	124	20	6	646	
	24.0	***29.6***	***31.2***	***22.4***	***21.0***	***24.9***	
Total live births §	**202731**	**2703**	**39722**	**8927**	**2852**	**259509**	
Male live births	**104422**	**1399**	**20175**	**4611**	**1438**	**133356**	
Female live births	**98308**	**1304**	**19547**	**4316**	**1414**	**126151**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births. Excludes male phenotype.
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Utah

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	100	2	102	
	4.3	***0.7***	***3.9***	
Trisomy 13	28	15	43	
	1.2	***5.2***	***1.7***	
Trisomy 18	61	32	93	
	2.6	***11.1***	***3.6***	
Trisomy 21 (Down syndrome)	216	201	417	
	9.4	***69.7***	***16.1***	
Total live births	**230654**	**28840**	**259509**	

**Total includes unknown maternal age

Notes
1.Data for this condition include congenital posterior urethral valves or posterior urethral obstruction only.

General comments
-Data for 2013 are provisional.
-Stillbirths are based on >=20 weeks gestation.
-Terminations include any weeks' gestation.

Vermont

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	2	0	0	0	0	2	
	0.7	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Anotia/microtia	4	0	0	1	0	5	
	1.4	***0.0***	***0.0***	***16.2***	***0.0***	***1.6***	
Aortic valve stenosis	18	0	1	0	0	19	
	6.3	***0.0***	***24.4***	***0.0***	***0.0***	***6.3***	
Atrial septal defect	224	4	6	4	1	242	
	78.9	***102.6***	***146.3***	***64.8***	***243.9***	***79.6***	
Atrioventricular septal defect (Endocardial cushion defect)	16	0	0	0	0	16	
	5.6	***0.0***	***0.0***	***0.0***	***0.0***	***5.3***	
Bladder exstrophy	1	0	0	1	0	2	
	0.4	***0.0***	***0.0***	***16.2***	***0.0***	***0.7***	
Cleft lip alone	17	0	0	0	0	18	
	6.0	***0.0***	***0.0***	***0.0***	***0.0***	***5.9***	
Cleft lip with cleft palate	13	0	0	0	0	13	
	4.6	***0.0***	***0.0***	***0.0***	***0.0***	***4.3***	
Cleft palate alone	27	0	1	0	0	28	
	9.5	***0.0***	***24.4***	***0.0***	***0.0***	***9.2***	
Coarctation of the aorta	21	0	0	0	0	21	
	7.4	***0.0***	***0.0***	***0.0***	***0.0***	***6.9***	
Common truncus (truncus arteriosus)	1	0	1	0	0	2	
	0.4	***0.0***	***24.4***	***0.0***	***0.0***	***0.7***	
Diaphragmatic hernia	13	0	0	0	0	13	
	4.6	***0.0***	***0.0***	***0.0***	***0.0***	***4.3***	
Double outlet right ventricle	4	0	0	0	0	4	
	1.4	***0.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Ebstein anomaly	1	0	0	0	0	1	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Encephalocele	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Esophageal atresia/tracheoesophageal fistula	9	0	0	1	0	10	
	3.2	***0.0***	***0.0***	***16.2***	***0.0***	***3.3***	
Gastroschisis	11	0	0	0	0	12	
	3.9	***0.0***	***0.0***	***0.0***	***0.0***	***3.9***	
Hypoplastic left heart syndrome	9	0	0	0	0	9	
	3.2	***0.0***	***0.0***	***0.0***	***0.0***	***3.0***	
Hypospadias*	115	3	0	0	0	119	
	77.7	***154.6***	***0.0***	***0.0***	***0.0***	***75.1***	
Omphalocele	4	1	0	0	0	5	
	1.4	***25.6***	***0.0***	***0.0***	***0.0***	***1.6***	
Pulmonary valve atresia and stenosis	47	1	1	1	0	51	
	16.6	***25.6***	***24.4***	***16.2***	***0.0***	***16.8***	
Pulmonary valve atresia	2	1	0	0	0	3	
	0.7	***25.6***	***0.0***	***0.0***	***0.0***	***1.0***	
Rectal and large intestinal atresia/stenosis	18	0	0	0	0	18	
	6.3	***0.0***	***0.0***	***0.0***	***0.0***	***5.9***	
Renal agenesis/hypoplasia	19	0	0	1	0	20	
	6.7	***0.0***	***0.0***	***16.2***	***0.0***	***6.6***	
Small intestinal atresia/stenosis	10	0	0	1	0	11	1
	3.5	***0.0***	***0.0***	***16.2***	***0.0***	***3.6***	
Spina bifida without anencephalus	6	0	0	0	0	6	
	2.1	***0.0***	***0.0***	***0.0***	***0.0***	***2.0***	
Tetralogy of Fallot	10	1	0	1	0	12	
	3.5	***25.6***	***0.0***	***16.2***	***0.0***	***3.9***	
Transposition of the great arteries (TGA)	7	0	0	1	0	8	
	2.5	***0.0***	***0.0***	***16.2***	***0.0***	***2.6***	
Dextro-transposition of great arteries (d-TGA)	5	0	0	1	0	6	
	1.8	***0.0***	***0.0***	***16.2***	***0.0***	***2.0***	
Tricuspid valve atresia and stenosis	2	0	0	0	0	2	
	0.7	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	

Vermont

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Trisomy 13	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Trisomy 18	6	0	0	0	0	6	
	2.1	***0.0***	***0.0***	***0.0***	***0.0***	***2.0***	
Trisomy 21 (Down syndrome)	32	0	0	1	0	33	
	11.3	***0.0***	***0.0***	***16.2***	***0.0***	***10.9***	
Ventricular septal defect	181	5	3	3	0	196	
	63.8	***128.2***	***73.2***	***48.6***	***0.0***	***64.5***	
Total live births	**28376**	**390**	**410**	**617**	**41**	**30391**	
Male live births	**14802**	**194**	**207**	**332**	**21**	**15848**	

*Hypospadias prevalence per 10,000 male live births
**Total includes unknown and other maternal race/ethnicity

Vermont

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	12	0	12	
	4.7	***0.0***	***3.9***	
Trisomy 13	0	0	0	
	0.0	***0.0***	***0.0***	
Trisomy 18	3	3	6	
	1.2	***6.1***	***2.0***	
Trisomy 21 (Down syndrome)	18	15	33	
	7.1	***30.5***	***10.9***	
Total live births	**25471**	**4917**	**30391**	

**Total includes unknown maternal age

Notes
1.Data for this condition include only small intestinal atresia.

Virginia

Birth Defects Counts and Prevalence 2009 - 2011 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	18	5	7	4	0	36	
	1.0	***0.7***	***1.8***	***1.8***	***0.0***	***1.2***	
Anophthalmia/microphthalmia	4	8	2	2	1	17	
	0.2	***1.2***	***0.5***	***0.9***	***23.1***	***0.5***	
Anotia/microtia	13	9	6	1	0	29	
	0.7	***1.3***	***1.6***	***0.4***	***0.0***	***0.9***	
Aortic valve stenosis	26	9	9	1	0	45	
	1.5	***1.3***	***2.3***	***0.4***	***0.0***	***1.4***	
Atrial septal defect	1657	843	603	335	4	3473	
	92.6	***126.3***	***156.1***	***150.2***	***92.4***	***111.9***	
Atrioventricular septal defect (Endocardial cushion defect)	52	38	13	4	0	108	
	2.9	***5.7***	***3.4***	***1.8***	***0.0***	***3.5***	
Biliary atresia	9	4	1	0	0	14	
	0.5	***0.6***	***0.3***	***0.0***	***0.0***	***0.5***	
Bladder exstrophy	2	0	0	0	0	2	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Choanal atresia	21	8	6	1	0	36	
	1.2	***1.2***	***1.6***	***0.4***	***0.0***	***1.2***	
Cleft lip alone	47	13	10	3	0	74	
	2.6	***1.9***	***2.6***	***1.3***	***0.0***	***2.4***	
Cleft lip with cleft palate	73	27	31	13	0	146	
	4.1	***4.0***	***8.0***	***5.8***	***0.0***	***4.7***	
Cleft palate alone	119	22	17	10	0	168	
	6.6	***3.3***	***4.4***	***4.5***	***0.0***	***5.4***	
Cloacal exstrophy	97	51	21	10	0	180	
	5.4	***7.6***	***5.4***	***4.5***	***0.0***	***5.8***	
Clubfoot	179	55	40	12	0	289	
	10.0	***8.2***	***10.4***	***5.4***	***0.0***	***9.3***	
Coarctation of the aorta	88	39	15	12	0	154	
	4.9	***5.8***	***3.9***	***5.4***	***0.0***	***5.0***	
Common truncus (truncus arteriosus)	12	9	2	0	0	23	
	0.7	***1.3***	***0.5***	***0.0***	***0.0***	***0.7***	
Congenital cataract	12	12	4	3	0	31	
	0.7	***1.8***	***1.0***	***1.3***	***0.0***	***1.0***	
Congenital posterior urethral valves	22	16	5	2	0	46	
	1.2	***2.4***	***1.3***	***0.9***	***0.0***	***1.5***	
Deletion 22q11.2	3	2	0	0	0	5	
	0.2	***0.3***	***0.0***	***0.0***	***0.0***	***0.2***	
Diaphragmatic hernia	42	16	11	0	0	69	
	2.3	***2.4***	***2.8***	***0.0***	***0.0***	***2.2***	
Double outlet right ventricle	31	18	9	8	0	66	
	1.7	***2.7***	***2.3***	***3.6***	***0.0***	***2.1***	
Ebstein anomaly	12	8	9	1	0	30	
	0.7	***1.2***	***2.3***	***0.4***	***0.0***	***1.0***	
Encephalocele	8	5	6	2	0	21	
	0.4	***0.7***	***1.6***	***0.9***	***0.0***	***0.7***	
Esophageal atresia/tracheoesophageal fistula	33	19	6	3	0	61	
	1.8	***2.8***	***1.6***	***1.3***	***0.0***	***2.0***	
Gastroschisis	59	22	16	3	0	100	
	3.3	***3.3***	***4.1***	***1.3***	***0.0***	***3.2***	
Holoprosencephaly	71	32	13	6	1	123	
	4.0	***4.8***	***3.4***	***2.7***	***23.1***	***4.0***	
Hypoplastic left heart syndrome	37	18	11	4	0	70	
	2.1	***2.7***	***2.8***	***1.8***	***0.0***	***2.3***	
Hypospadias*	597	181	63	53	1	900	
	64.8	***53.4***	***32.0***	***46.2***	***45.5***	***56.6***	
Interrupted aortic arch	5	9	2	0	0	16	
	0.3	***1.3***	***0.5***	***0.0***	***0.0***	***0.5***	
Limb deficiencies (reduction defects)	51	17	7	4	0	79	
	2.8	***2.5***	***1.8***	***1.8***	***0.0***	***2.5***	

Virginia

Birth Defects Counts and Prevalence 2009 - 2011 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	15	10	3	3	0	31	
	0.8	***1.5***	***0.8***	***1.3***	***0.0***	***1.0***	
Pulmonary valve atresia and stenosis	171	98	60	43	1	374	
	9.6	***14.7***	***15.5***	***19.3***	***23.1***	***12.0***	
Rectal and large intestinal atresia/stenosis	72	27	23	8	0	131	
	4.0	***4.0***	***6.0***	***3.6***	***0.0***	***4.2***	
Renal agenesis/hypoplasia	63	31	13	4	0	114	
	3.5	***4.6***	***3.4***	***1.8***	***0.0***	***3.7***	
Single ventricle	24	12	2	1	0	39	
	1.3	***1.8***	***0.5***	***0.4***	***0.0***	***1.3***	
Small intestinal atresia/stenosis	64	26	15	6	0	114	
	3.6	***3.9***	***3.9***	***2.7***	***0.0***	***3.7***	
Spina bifida without anencephalus	37	17	17	3	0	74	
	2.1	***2.5***	***4.4***	***1.3***	***0.0***	***2.4***	
Tetralogy of Fallot	76	46	15	12	1	151	
	4.2	***6.9***	***3.9***	***5.4***	***23.1***	***4.9***	
Total anomalous pulmonary venous connection	18	2	5	5	0	30	
	1.0	***0.3***	***1.3***	***2.2***	***0.0***	***1.0***	
Transposition of the great arteries (TGA)	73	33	9	12	0	129	
	4.1	***4.9***	***2.3***	***5.4***	***0.0***	***4.2***	
Tricuspid valve atresia and stenosis	34	12	10	4	0	60	
	1.9	***1.8***	***2.6***	***1.8***	***0.0***	***1.9***	
Trisomy 13	10	3	5	1	1	20	
	0.6	***0.4***	***1.3***	***0.4***	***23.1***	***0.6***	
Trisomy 18	18	12	13	1	0	44	
	1.0	***1.8***	***3.4***	***0.4***	***0.0***	***1.4***	
Trisomy 21 (Down syndrome)	196	97	70	17	3	390	
	10.9	***14.5***	***18.1***	***7.6***	***69.3***	***12.6***	
Turner syndrome†	14	5	5	1	0	25	
	1.6	***1.5***	***2.6***	***0.9***	***0.0***	***1.7***	
Ventricular septal defect	790	287	239	109	10	1438	1
	44.1	***43.0***	***61.9***	***48.9***	***230.9***	***46.3***	
Total live births §	**179002**	**66723**	**38628**	**22297**	**433**	**310438**	
Male live births	**92070**	**33893**	**19683**	**11469**	**220**	**159053**	
Female live births	**86927**	**32829**	**18945**	**10827**	**213**	**151378**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity
§Total live births includes unknown gender

Virginia

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2011 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	99	1	100	
	3.8	***0.2***	***3.2***	
Trisomy 13	8	12	20	
	0.3	***2.3***	***0.6***	
Trisomy 18	18	26	44	
	0.7	***5.1***	***1.4***	
Trisomy 21 (Down syndrome)	211	165	390	
	8.2	***32.3***	***12.6***	
Total live births	**258851**	**51126**	**310438**	

**Total includes unknown maternal age

Notes
1.Data for this condition exclude probable cases.

General comments
-Fetal death defined as death prior to the complete expulsion or extraction from its mother of a product of human conception, irrespective of the duration of pregnancy.

West Virginia

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	44	0	1	0	0	46	
	5.2	***0.0***	***9.5***	***0.0***	***0.0***	***5.0***	
Anophthalmia/microphthalmia	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Anotia/microtia	3	0	0	0	0	3	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Aortic valve stenosis	15	0	0	0	0	17	
	1.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.8***	
Atrial septal defect	1441	69	7	8	0	1590	
	171.6	***209.9***	***66.2***	***79.6***	***0.0***	***172.4***	
Atrioventricular septal defect (Endocardial cushion defect)	27	2	0	0	0	30	
	3.2	***6.1***	***0.0***	***0.0***	***0.0***	***3.3***	
Biliary atresia	6	1	0	0	0	8	
	0.7	***3.0***	***0.0***	***0.0***	***0.0***	***0.9***	
Bladder exstrophy	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Choanal atresia	9	1	0	0	0	12	
	1.1	***3.0***	***0.0***	***0.0***	***0.0***	***1.3***	
Cleft lip alone	1	0	0	0	0	1	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Cleft lip with cleft palate	50	1	0	0	0	53	
	6.0	***3.0***	***0.0***	***0.0***	***0.0***	***5.7***	
Cleft palate alone	71	0	0	0	0	72	
	8.5	***0.0***	***0.0***	***0.0***	***0.0***	***7.8***	
Cloacal exstrophy	28	2	0	1	0	33	
	3.3	***6.1***	***0.0***	***10.0***	***0.0***	***3.6***	
Clubfoot	170	4	1	0	0	181	
	20.2	***12.2***	***9.5***	***0.0***	***0.0***	***19.6***	
Coarctation of the aorta	43	0	0	0	0	45	
	5.1	***0.0***	***0.0***	***0.0***	***0.0***	***4.9***	
Common truncus (truncus arteriosus)	82	3	0	1	0	86	
	9.8	***9.1***	***0.0***	***10.0***	***0.0***	***9.3***	
Congenital cataract	4	0	0	1	0	5	
	0.5	***0.0***	***0.0***	***10.0***	***0.0***	***0.5***	
Congenital posterior urethral valves	3	1	0	0	0	4	
	0.4	***3.0***	***0.0***	***0.0***	***0.0***	***0.4***	
Deletion 22q11.2	2	0	0	0	0	2	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.2***	
Diaphragmatic hernia	25	1	0	0	0	28	
	3.0	***3.0***	***0.0***	***0.0***	***0.0***	***3.0***	
Double outlet right ventricle	23	2	0	0	0	26	
	2.7	***6.1***	***0.0***	***0.0***	***0.0***	***2.8***	
Ebstein anomaly	16	0	0	0	0	17	
	1.9	***0.0***	***0.0***	***0.0***	***0.0***	***1.8***	
Encephalocele	3	0	0	0	0	3	
	0.4	***0.0***	***0.0***	***0.0***	***0.0***	***0.3***	
Esophageal atresia/tracheoesophageal fistula	16	2	0	0	0	21	
	1.9	***6.1***	***0.0***	***0.0***	***0.0***	***2.3***	
Gastroschisis	4	0	0	0	0	4	1
	2.4	***0.0***	***0.0***	***0.0***	***0.0***	***2.2***	
Holoprosencephaly	42	0	0	0	0	46	
	5.0	***0.0***	***0.0***	***0.0***	***0.0***	***5.0***	
Hypoplastic left heart syndrome	16	2	0	0	0	21	
	1.9	***6.1***	***0.0***	***0.0***	***0.0***	***2.3***	
Hypospadias*	242	10	0	0	0	257	
	56.7	***59.2***	***0.0***	***0.0***	***0.0***	***54.7***	
Interrupted aortic arch	6	1	0	0	0	7	
	0.7	***3.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Limb deficiencies (reduction defects)	15	1	0	0	0	17	
	1.8	***3.0***	***0.0***	***0.0***	***0.0***	***1.8***	

West Virginia

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	3	0	0	0	0	3	1
	1.8	***0.0***	***0.0***	***0.0***	***0.0***	***1.6***	
Pulmonary valve atresia and stenosis	55	0	0	1	0	60	
	6.5	***0.0***	***0.0***	***10.0***	***0.0***	***6.5***	
Pulmonary valve atresia	11	0	0	0	0	11	
	1.3	***0.0***	***0.0***	***0.0***	***0.0***	***1.2***	
Rectal and large intestinal atresia/stenosis	42	0	0	0	0	42	
	5.0	***0.0***	***0.0***	***0.0***	***0.0***	***4.6***	
Renal agenesis/hypoplasia	40	1	0	0	0	43	
	4.8	***3.0***	***0.0***	***0.0***	***0.0***	***4.7***	
Single ventricle	6	0	0	0	0	8	
	0.7	***0.0***	***0.0***	***0.0***	***0.0***	***0.9***	
Small intestinal atresia/stenosis	33	0	0	0	0	34	
	3.9	***0.0***	***0.0***	***0.0***	***0.0***	***3.7***	
Spina bifida without anencephalus	27	0	0	1	0	29	
	3.2	***0.0***	***0.0***	***10.0***	***0.0***	***3.1***	
Tetralogy of Fallot	37	2	1	0	0	44	
	4.4	***6.1***	***9.5***	***0.0***	***0.0***	***4.8***	
Total anomalous pulmonary venous connection	7	0	0	1	0	8	
	0.8	***0.0***	***0.0***	***10.0***	***0.0***	***0.9***	
Transposition of the great arteries (TGA)	27	0	0	0	0	29	
	3.2	***0.0***	***0.0***	***0.0***	***0.0***	***3.1***	
Dextro-transposition of great arteries (d-TGA)	25	0	0	0	0	25	
	3.0	***0.0***	***0.0***	***0.0***	***0.0***	***2.7***	
Tricuspid valve atresia and stenosis	5	0	0	0	0	5	
	0.6	***0.0***	***0.0***	***0.0***	***0.0***	***0.5***	
Trisomy 13	5	1	0	0	0	7	
	0.6	***3.0***	***0.0***	***0.0***	***0.0***	***0.8***	
Trisomy 18	13	2	0	0	0	15	
	1.5	***6.1***	***0.0***	***0.0***	***0.0***	***1.6***	
Trisomy 21 (Down syndrome)	60	3	1	1	0	74	
	7.1	***9.1***	***9.5***	***10.0***	***0.0***	***8.0***	
Turner syndrome†	1	0	0	0	0	3	
	0.2	***0.0***	***0.0***	***0.0***	***0.0***	***0.7***	
Ventricular septal defect	333	12	0	3	0	372	
	39.7	***36.5***	***0.0***	***29.9***	***0.0***	***40.3***	
Total live births	**83974**	**3287**	**1058**	**1005**	**86**	**92246**	
Male live births	**42694**	**1690**	**536**	**508**	**40**	**46943**	
Female live births	**41280**	**1597**	**522**	**497**	**46**	**45303**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

West Virginia

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	4	0	4	1
	2.4	***0.0***	***2.2***	
Trisomy 13	6	0	7	
	0.7	***0.0***	***0.8***	
Trisomy 18	10	5	15	
	1.2	***5.6***	***1.6***	
Trisomy 21 (Down syndrome)	41	20	74	
	4.9	***22.4***	***8.0***	
Total live births	**83264**	**8936**	**92246**	

**Total includes unknown maternal age

Notes
1.Data for this condition begin in 2013.

General comments
-Probable cases are included.

Wisconsin

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	22	3	4	3	2	34	
	0.9	***0.9***	***1.3***	***2.1***	***4.6***	***1.1***	
Anophthalmia/microphthalmia	9	0	1	0	0	10	
	0.4	***0.0***	***0.3***	***0.0***	***0.0***	***0.3***	
Anotia/microtia	16	2	9	1	1	30	
	0.7	***0.6***	***2.8***	***0.7***	***2.3***	***0.9***	
Aortic valve stenosis	18	3	0	0	1	22	
	0.8	***0.9***	***0.0***	***0.0***	***2.3***	***0.7***	
Atrial septal defect	1128	149	153	57	38	1543	
	48.5	***46.5***	***47.8***	***39.1***	***88.3***	***48.2***	
Atrioventricular septal defect (Endocardial cushion defect)	45	4	6	2	0	59	
	1.9	***1.2***	***1.9***	***1.4***	***0.0***	***1.8***	
Biliary atresia	2	0	0	0	0	2	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Bladder exstrophy	5	0	1	0	0	7	
	0.2	***0.0***	***0.3***	***0.0***	***0.0***	***0.2***	
Choanal atresia	29	1	4	2	0	37	
	1.2	***0.3***	***1.3***	***1.4***	***0.0***	***1.2***	
Cleft lip alone	68	5	7	5	0	85	
	2.9	***1.6***	***2.2***	***3.4***	***0.0***	***2.7***	
Cleft lip with cleft palate	50	8	9	4	0	71	
	2.1	***2.5***	***2.8***	***2.7***	***0.0***	***2.2***	
Cleft palate alone	131	9	15	10	4	172	
	5.6	***2.8***	***4.7***	***6.9***	***9.3***	***5.4***	
Cloacal exstrophy	91	14	12	8	0	126	
	3.9	***4.4***	***3.8***	***5.5***	***0.0***	***3.9***	
Clubfoot	373	36	35	10	5	468	
	16.0	***11.2***	***10.9***	***6.9***	***11.6***	***14.6***	
Coarctation of the aorta	70	9	8	1	1	90	
	3.0	***2.8***	***2.5***	***0.7***	***2.3***	***2.8***	
Common truncus (truncus arteriosus)	5	0	2	0	0	7	
	0.2	***0.0***	***0.6***	***0.0***	***0.0***	***0.2***	
Congenital cataract	15	1	5	0	1	23	
	0.6	***0.3***	***1.6***	***0.0***	***2.3***	***0.7***	
Congenital posterior urethral valves	12	3	1	3	2	21	
	0.5	***0.9***	***0.3***	***2.1***	***4.6***	***0.7***	
Craniosynostosis	0	0	0	0	0	0	
	0.0	***0.0***	***0.0***	***0.0***	***0.0***	***0.0***	
Deletion 22q11.2	2	0	0	0	0	2	
	0.1	***0.0***	***0.0***	***0.0***	***0.0***	***0.1***	
Diaphragmatic hernia	52	3	6	1	2	64	
	2.2	***0.9***	***1.9***	***0.7***	***4.6***	***2.0***	
Double outlet right ventricle	21	4	4	0	0	30	
	0.9	***1.2***	***1.3***	***0.0***	***0.0***	***0.9***	
Ebstein anomaly	12	0	0	1	1	15	
	0.5	***0.0***	***0.0***	***0.7***	***2.3***	***0.5***	
Encephalocele	7	0	2	1	0	11	
	0.3	***0.0***	***0.6***	***0.7***	***0.0***	***0.3***	
Esophageal atresia/tracheoesophageal fistula	45	6	5	3	0	61	
	1.9	***1.9***	***1.6***	***2.1***	***0.0***	***1.9***	
Holoprosencephaly	57	9	6	3	1	81	
	2.4	***2.8***	***1.9***	***2.1***	***2.3***	***2.5***	
Hypoplastic left heart syndrome	25	6	2	0	1	34	
	1.1	***1.9***	***0.6***	***0.0***	***2.3***	***1.1***	
Hypospadias*	915	113	62	27	8	1137	
	76.6	***69.7***	***38.1***	***35.9***	***35.9***	***69.4***	
Interrupted aortic arch	8	1	0	2	1	12	
	0.3	***0.3***	***0.0***	***1.4***	***2.3***	***0.4***	
Limb deficiencies (reduction defects)	76	9	10	5	2	102	
	3.3	***2.8***	***3.1***	***3.4***	***4.6***	***3.2***	

Wisconsin

Birth Defects Counts and Prevalence 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Pulmonary valve atresia and stenosis	44	11	5	2	1	63	
	1.9	***3.4***	***1.6***	***1.4***	***2.3***	***2.0***	
Pulmonary valve atresia	4	0	0	1	0	5	
	0.2	***0.0***	***0.0***	***0.7***	***0.0***	***0.2***	
Rectal and large intestinal atresia/stenosis	72	5	8	5	2	96	
	3.1	***1.6***	***2.5***	***3.4***	***4.6***	***3.0***	
Renal agenesis/hypoplasia	131	10	8	4	0	154	
	5.6	***3.1***	***2.5***	***2.7***	***0.0***	***4.8***	
Single ventricle	2	0	0	0	1	3	
	0.1	***0.0***	***0.0***	***0.0***	***2.3***	***0.1***	
Small intestinal atresia/stenosis	71	12	11	6	5	105	
	3.1	***3.7***	***3.4***	***4.1***	***11.6***	***3.3***	
Spina bifida without anencephalus	58	9	12	3	1	83	
	2.5	***2.8***	***3.8***	***2.1***	***2.3***	***2.6***	
Tetralogy of Fallot	40	8	8	5	0	61	
	1.7	***2.5***	***2.5***	***3.4***	***0.0***	***1.9***	
Total anomalous pulmonary venous connection	3	1	1	0	0	5	
	0.1	***0.3***	***0.3***	***0.0***	***0.0***	***0.2***	
Transposition of the great arteries (TGA)	32	2	5	0	2	43	
	1.4	***0.6***	***1.6***	***0.0***	***4.6***	***1.3***	
Dextro-transposition of great arteries (d-TGA)	18	2	2	0	2	26	
	0.8	***0.6***	***0.6***	***0.0***	***4.6***	***0.8***	
Tricuspid valve atresia and stenosis	5	0	1	1	0	7	
	0.2	***0.0***	***0.3***	***0.7***	***0.0***	***0.2***	
Trisomy 13	15	1	2	2	0	21	
	0.6	***0.3***	***0.6***	***1.4***	***0.0***	***0.7***	
Trisomy 18	62	5	7	3	0	80	
	2.7	***1.6***	***2.2***	***2.1***	***0.0***	***2.5***	
Trisomy 21 (Down syndrome)	259	22	49	22	4	358	
	11.1	***6.9***	***15.3***	***15.1***	***9.3***	***11.2***	
Turner syndrome†	10	2	0	0	0	12	
	0.9	***1.3***	***0.0***	***0.0***	***0.0***	***0.8***	
Ventricular septal defect	596	69	110	37	15	833	
	25.6	***21.5***	***34.4***	***25.4***	***34.9***	***26.0***	
Total live births	**232705**	**32069**	**31983**	**14571**	**4303**	**319903**	
Male live births	**119391**	**16204**	**16258**	**7522**	**2230**	**163784**	
Female live births	**113314**	**15865**	**15725**	**7049**	**2073**	**156119**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

Wisconsin

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2013 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Trisomy 13	12	9	21	
	0.4	***2.2***	***0.7***	
Trisomy 18	45	35	80	
	1.6	***8.6***	***2.5***	
Trisomy 21 (Down syndrome)	184	174	358	
	6.6	***42.6***	***11.2***	
Total live births	**278996**	**40879**	**319903**	

**Total includes unknown maternal age

General comments
-Fetal deaths defined as 20 weeks or greater gestation.

Department of Defense

Birth Defects Counts and Prevalence 2009 - 2010.13 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Anencephalus	31	4	3	1	1	40	
	0.8	***0.5***	***0.4***	***0.3***	***0.9***	***0.7***	
Anophthalmia/microphthalmia	55	19	11	9	2	98	
	1.3	***2.3***	***1.6***	***3.1***	***1.9***	***1.6***	
Anotia/microtia	86	9	25	15	3	138	
	2.1	***1.1***	***3.7***	***5.2***	***2.8***	***2.3***	
Aortic valve stenosis	146	24	13	5	4	197	
	3.6	***3.0***	***1.9***	***1.7***	***3.8***	***3.2***	
Atrial septal defect	4308	917	716	246	86	6410	1
	105.5	***112.8***	***105.5***	***84.6***	***81.1***	***104.9***	
Atrioventricular septal defect (Endocardial cushion defect)	255	55	31	12	1	358	2
	6.2	***6.8***	***4.6***	***4.1***	***0.9***	***5.9***	
Biliary atresia	37	16	12	2	2	70	
	0.9	***2.0***	***1.8***	***0.7***	***1.9***	***1.1***	
Bladder exstrophy	21	1	0	0	0	23	
	0.5	***0.1***	***0.0***	***0.0***	***0.0***	***0.4***	
Choanal atresia	104	19	18	5	2	152	
	2.5	***2.3***	***2.7***	***1.7***	***1.9***	***2.5***	
Cleft lip alone	318	33	33	28	7	421	
	7.8	***4.1***	***4.9***	***9.6***	***6.6***	***6.9***	
Cleft lip with cleft palate	346	44	45	28	9	480	
	8.5	***5.4***	***6.6***	***9.6***	***8.5***	***7.9***	
Cleft palate alone	503	68	69	37	11	697	
	12.3	***8.4***	***10.2***	***12.7***	***10.4***	***11.4***	
Cloacal exstrophy	343	64	49	16	8	493	
	8.4	***7.9***	***7.2***	***5.5***	***7.5***	***8.1***	
Clubfoot	904	160	138	46	21	1292	
	22.1	***19.7***	***20.3***	***15.8***	***19.8***	***21.2***	
Coarctation of the aorta	424	71	41	20	12	586	
	10.4	***8.7***	***6.0***	***6.9***	***11.3***	***9.6***	
Common truncus (truncus arteriosus)	96	17	9	7	1	133	
	2.4	***2.1***	***1.3***	***2.4***	***0.9***	***2.2***	
Congenital cataract	134	32	30	8	2	210	
	3.3	***3.9***	***4.4***	***2.8***	***1.9***	***3.4***	
Congenital posterior urethral valves	86	12	7	5	4	117	
	2.1	***1.5***	***1.0***	***1.7***	***3.8***	***1.9***	
Deletion 22q11.2	42	9	6	1	2	60	
	1.0	***1.1***	***0.9***	***0.3***	***1.9***	***1.0***	
Diaphragmatic hernia	179	41	29	14	7	273	
	4.4	***5.0***	***4.3***	***4.8***	***6.6***	***4.5***	
Double outlet right ventricle	129	26	22	11	1	193	
	3.2	***3.2***	***3.2***	***3.8***	***0.9***	***3.2***	
Ebstein anomaly	60	9	9	3	3	85	
	1.5	***1.1***	***1.3***	***1.0***	***2.8***	***1.4***	
Encephalocele	43	8	9	1	3	65	
	1.1	***1.0***	***1.3***	***0.3***	***2.8***	***1.1***	
Esophageal atresia/tracheoesophageal fistula	118	25	15	5	1	165	
	2.9	***3.1***	***2.2***	***1.7***	***0.9***	***2.7***	
Gastroschisis	220	18	43	11	5	302	3
	6.7	***2.8***	***7.9***	***4.6***	***5.9***	***6.1***	
Holoprosencephaly	299	38	37	13	10	411	
	7.3	***4.7***	***5.5***	***4.5***	***9.4***	***6.7***	
Hypoplastic left heart syndrome	188	38	19	7	2	261	
	4.6	***4.7***	***2.8***	***2.4***	***1.9***	***4.3***	
Hypospadias*	2358	415	261	137	58	3292	
	111.8	***100.2***	***75.1***	***91.1***	***107.4***	***104.7***	
Interrupted aortic arch	54	10	4	4	1	76	
	1.3	***1.2***	***0.6***	***1.4***	***0.9***	***1.2***	
Limb deficiencies (reduction defects)	233	52	40	8	5	345	
	5.7	***6.4***	***5.9***	***2.8***	***4.7***	***5.6***	

Department of Defense

Birth Defects Counts and Prevalence 2009 - 2010.13 (Prevalence per 10,000 Live Births)

	Maternal Race/Ethnicity						
Defect	**White, Non-Hispanic**	**Black, Non-Hispanic**	**Hispanic**	**Asian or Pacific Islander, Non-Hispanic**	**American Indian or Alaska Native, Non-Hispanic**	**Total****	**Notes**
Omphalocele	69	18	9	4	0	101	3
	2.1	***2.8***	***1.6***	***1.7***	***0.0***	***2.0***	
Pulmonary valve atresia and stenosis	726	209	131	45	13	1148	
	17.8	***25.7***	***19.3***	***15.5***	***12.3***	***18.8***	
Pulmonary valve atresia	114	29	17	7	0	170	
	2.8	***3.6***	***2.5***	***2.4***	***0.0***	***2.8***	
Rectal and large intestinal atresia/stenosis	267	39	34	23	4	374	
	6.5	***4.8***	***5.0***	***7.9***	***3.8***	***6.1***	
Renal agenesis/hypoplasia	271	52	48	22	5	406	
	6.6	***6.4***	***7.1***	***7.6***	***4.7***	***6.6***	
Single ventricle	122	28	15	5	1	176	
	3.0	***3.4***	***2.2***	***1.7***	***0.9***	***2.9***	
Small intestinal atresia/stenosis	227	62	37	13	5	350	
	5.6	***7.6***	***5.5***	***4.5***	***4.7***	***5.7***	
Spina bifida without anencephalus	199	31	28	7	12	282	
	4.9	***3.8***	***4.1***	***2.4***	***11.3***	***4.6***	
Tetralogy of Fallot	250	57	47	27	4	391	
	6.1	***7.0***	***6.9***	***9.3***	***3.8***	***6.4***	
Total anomalous pulmonary venous connection	55	19	13	5	0	95	
	1.3	***2.3***	***1.9***	***1.7***	***0.0***	***1.6***	
Transposition of the great arteries (TGA)	159	17	16	12	1	211	
	3.9	***2.1***	***2.4***	***4.1***	***0.9***	***3.5***	
Dextro-transposition of great arteries (d-TGA)	146	15	16	12	1	195	
	3.6	***1.8***	***2.4***	***4.1***	***0.9***	***3.2***	
Tricuspid valve atresia and stenosis	75	20	7	7	0	113	
	1.8	***2.5***	***1.0***	***2.4***	***0.0***	***1.8***	
Trisomy 13	38	19	8	2	0	68	
	0.9	***2.3***	***1.2***	***0.7***	***0.0***	***1.1***	
Trisomy 18	67	20	14	1	0	105	
	1.6	***2.5***	***2.1***	***0.3***	***0.0***	***1.7***	
Trisomy 21 (Down syndrome)	601	97	91	33	11	852	
	14.7	***11.9***	***13.4***	***11.4***	***10.4***	***13.9***	
Turner syndrome†	53	5	7	2	2	70	
	2.7	***1.3***	***2.1***	***1.4***	***3.8***	***2.4***	
Ventricular septal defect	3103	539	477	174	69	4443	4
	76.0	***66.3***	***70.3***	***59.8***	***65.1***	***72.7***	
Total live births	**408404**	**81279**	**67847**	**29074**	**10604**	**610830**	
Male live births	**210899**	**41415**	**34761**	**15037**	**5400**	**314557**	
Female live births	**197505**	**39864**	**33086**	**14037**	**5204**	**296273**	

*Hypospadias prevalence per 10,000 male live births
†Turner syndrome prevalence per 10,000 female live births
**Total includes unknown and other maternal race/ethnicity

Department of Defense

Trisomy and Gastroschisis Counts and Prevalence by Maternal Age 2009 - 2010.13 (Prevalence per 10,000 Live Births)

	Maternal Age (years)			
Defect	**Less than 35**	**35+**	**Total****	**Notes**
Gastroschisis	281	2	302	3
	6.5	***0.4***	***6.1***	
Trisomy 13	42	24	68	
	0.8	***4.3***	***1.1***	
Trisomy 18	66	34	105	
	1.2	***6.1***	***1.7***	
Trisomy 21 (Down syndrome)	513	310	852	
	9.6	***55.5***	***13.9***	
Total live births	**532890**	**55831**	**610830**	

**Total includes unknown maternal age

Notes
1.Data for this condition include patent foramen ovale.
2.Data for this condition include inlet ventricular septal defect.
3.Data for this condition begin in 2010.
4.Data for this condition include inlet ventricular septal defect and probable ventricular septal defect.

General comments
-Data for conditions include live births only
-Race/ethnicity for the Department of Defense Birth and Infant Health Registry is based on the military parent through whom the infant receives military health care benefits. This may be the infant's mother or father.

STATE BIRTH DEFECTS SURVEILLANCE PROGRAM DIRECTORY

Updated August 2016

Prepared by the National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention

Acknowledgement: State birth defects program directors provided the information for the directory. Their names can be found under the 'contact' section of each state profile.

Alabama

Program status: No surveillance program

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Alaska

Alaska Birth Defects Registry (ABDR)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 1996
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health)
Population covered annually: 11,000
Statewide: Yes
Current legislation or rule: 7 AAC 27.012
Legislation year enacted: 1996

Case Definition
Outcomes covered: Selected major birth defects based on ICD-10-CM code list
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Birth to sixth birthday
Residence: In and out of state births to Alaska residents

Surveillance Methods
Case ascertainment: Passive case-finding with case confirmation
Vital Records: Birth certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Genetics clinics, specialty clinics (heart, cleft lip/palate, neurodevelopmental), MIMR (FIMR), public health nursing, Alaska Dept. of Behavioral Health (AKAIMS)
Delivery Hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.
Pediatric & tertiary care hospitals: Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-10 code.
Third party payers: Medicaid databases, Indian health services
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Physician reports, Alaska Health Information Exchange, AK AIMS (Alaska Dept. of Behavioral Health)

Case Ascertainment
Conditions warranting chart review in the newborn period: All Codes included in the current NBDPN list of birth defects listing (see: http://www.nbdpn.org/docs/Appendix_3_1_BirthDefectsDescriptions2015.pdf) are sampled for review. Other collected conditions/codes will are sampled and reviewed based upon incoming requests and/or need.
Coding: ICD-10-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access

Data Analysis
Data analysis software: SAS, Access, R
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Rates by demographic and other variables, Time trends, Needs assessment, Grant proposals, Education/public awareness

System integration
System links: Link case finding data to final birth file
System integration: No.

Funding
Funding source: 20% General state funds, 80% MCH funds

Other
Web site:
http://dhss.alaska.gov/dph/wcfh/Pages/mchepi/abdr/default.aspx
Surveillance reports on file:
Http://dhss.alaska.gov/dph/wcfh/Pages/mchepi/mchdatabook/default.aspx

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Arizona

Arizona Birth Defects Monitoring Program (ABDMP)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs
Program status: Currently collecting data
Start Year: 1986
Earliest year of available data: 1986
Organizational location: Department of Health (Public Health Statistics)
Population covered annually: 87,000
Statewide: Yes
Current legislation or rule: Legislation enacted 1988; Rule effective 1991 Statute: 36-133; Rule: Arizona Administrative Code R9-4-Article 5
Legislation year enacted: 1988

Case Definition

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Any gestational age or weight if a fetal death certificate was issued)
Age: Up to one year after delivery. If the nature of a defect diagnosed in the first year of life is more precisely diagnosed later in the child's life, and this information is contained in the chart at the time of our review, then the more precise diagnosis and information is used.
Residence: Arizona birth to an Arizona resident mother

Surveillance Methods

Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Fetal birth certificate, Hospital Discharge Database
Delivery Hospitals: Disease index or discharge index
Pediatric & tertiary care hospitals: Disease index or discharge index
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Midwifery Facilities

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff
Database collection and storage: Access, Oracle

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file

Funding

Funding source: 17% General state funds, 20% MCH funds, 63% CDC grant

Other

Web site: http://azdhs.gov/phs/phstats/bdr/index.htm and azhealth.gov/birth-defects
Surveillance reports on file: Annual Reports
Additional information on file: Fact Sheets; Resources
Other comments: To contact the ABDMP email abdmp@azdhs.gov

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Arkansas

Arkansas Reproductive Health Monitoring System (ARHMS)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Legislators
Program status: Currently collecting data
Start Year: 1980
Earliest year of available data: 1980
Organizational location: University
Population covered annually: 40,000
Statewide: Yes
Current legislation or rule: Acts 1985, No. 214
Legislation year enacted: 1985

Case Definition
Outcomes covered: Major congenital malformations, 740.000-759.990, plus select others outside this range
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Birth to second birthday
Residence: In and out of state births to Arkansas residents

Surveillance Methods
Case ascertainment: Active Case Finding
Vital Records: Birth certificates
Delivery Hospitals: Disease index or discharge index, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 code.
Pediatric & tertiary care hospitals: Disease index or discharge index, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Reports are generated by the health information management departments, within hospitals and health care facilities, for any child encountered with a reportable ICD-9 code.
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal diagnostic information
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access

Data Analysis
Data analysis software: SAS, Access, STATA
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness, Prevention projects

System integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: No

Funding
Funding source: 100% General state funds

Other
Web site: http://arbirthdefectsresearch.uams.edu/
Surveillance reports on file: Online data query system available through the Arkansas Department of Health: http://www.healthy.arkansas.gov/programsServices/healthStatistics/Pages/Statistics.aspx

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California

California Birth Defects Monitoring Program (CBDMP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Universities
Program status: Currently collecting data
Start Year: 1983
Earliest year of available data: 1983
Organizational location: Department of Health (Genetic Disease Screening Program, Center for Family Health)
Population covered annually: 70,000
Statewide: No, CBDMP currently monitors a sampling of California births that are demographically similar to the state as a whole and whose birth defects rates and trends have been reflective of those throughout California. Furthermore, CBDMP has statutory authority to conduct active surveillance anywhere in the state when warranted by environmental incidents or concerns.
Current legislation or rule: California Health and Safety Code, Division 102, Part 2, Chapter 1, Sections 103825-103855, effective 1982, recodified 1996
Legislation year enacted: 1982

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: One year
Residence: In-state births to residents of counties monitored by CBDMP

Surveillance Methods
Case ascertainment: Active Case Finding
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, GI condition (e.g. intestinal blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codable defect
Coding: CDC BPA codes but modified for use in California

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: SQL server

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Validity checks are done on all abstracts
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Grant proposals, Education/public awareness

System integration
System links: Link case finding data to final birth file, Hospital discharge. CBDMP links case finding data to final vital statistics fetal death files

Funding
Funding source: 100% CBDMP Special Fund
Web site: www.cdph.ca.gov/programs/CBDMP
Surveillance reports on file: Birth defect fact sheets and California regional birth defect data available on the website.
Additional information on file: Please send inquiries to mchinet@cdph.ca.gov

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Centers for Disease Control and Prevention (Metropolitan Atlanta Congenital Defects Program)

Metropolitan Atlanta Congenital Defects Program (MACDP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Laboratories, Prenatal Diagnostic Providers
Program status: Currently collecting data
Start Year: 1967
Earliest year of available data: 1968
Organizational location: CDC, National Center on Birth Defects and Developmental Disabilities
Population covered annually: 35,000
Statewide: No, Births to mothers residing within one of three central counties in the metropolitan Atlanta area of the state of Georgia

Case Definition
Outcomes covered: All major structural and genetic birth defects
Pregnancy outcome: Livebirths (>=20 weeks), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: Before 6 years of age
Residence: Births to mothers residing in one of three central metropolitan Atlanta counties

Surveillance Methods
Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Fetal birth certificate
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Induction logs and miscarriage logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (Birth weight < 2500 grams and/or 20-36 weeks gestation), All stillborn infants, All neonatal deaths, All elective abortions, All infants with low APGAR scores, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access, SQL Server, SAS

Data Analysis
Data analysis software: SPSS, SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Education/public awareness, Prevention projects, Survival analysis

System integration
System links: Link case finding data to final birth file, National Death Index; Death and Fetal Death Records; Laboratory Records

Funding
Funding source: 100% Intramural CDC funding
Web site: http://www.cdc.gov/ncbddd/bd/macdp.htm
Surveillance reports on file: MACDP 40th Anniversary Surveillance Report
Additional information on file: CDC/BPA Defect Code; Including prenatal diagnoses in BD monitoring

Comments: The 40th Anniversary Surveillance Report was published: Correa A, Cragan JD, Kucik JE, et al. Reporting birth defects surveillance data 1968-2003. Birth Defects Research Part A. 2007;79(2):65-186.

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Colorado

Colorado Responds to Children with Special Needs Section (CRCSN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 1988
Earliest year of available data: 1989
Organizational location: Department of Health (Vital Statistics, Center for Health and Environmental Data (CHED))
Population covered annually: 66,545 (2015)
Statewide: Yes
Current legislation or rule: Colorado Revised Statutes (CRS) 25-1.5-101.25-1.5-105
Legislation year enacted: 1985

Case Definition
Outcomes covered: Structural birth defects, fetal alcohol syndrome,selected genetic and metabolic disorders; muscular dystrophy;selected developmental disabilities; very low birth weight (less than 1500 grams);others with medical risk factors for developmental delay.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages, Less than 20 weeks gestation, 20 weeks gestation and greater)
Age: Up to the 5th birthday (up to 10th birthday for fetal alcohol syndrome)
Residence: Events occurring in-state- or out-of-state Colorado residents

Surveillance Methods
Case ascertainment: Active Case Finding, Passive case-finding with case confirmation
Vital Records: Birth certificates, Death certificates, Fetal birth certificate
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in the newborn period: All stillborn infants, Selected chart reviews for prenatal to age 3: for statistical trends monitoring (23 conditions-catagories); fetal alcohol syndrome (to age 10), active case ascertainment data sources
Coding: ICD-9-CM, Extended code utilized to describe syndromes, further detail of a condition and to specify status.

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Gravidity/parity, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), 99% of data are collected in electronic format

Data Analysis
Data analysis software: Epi-Info, SAS, Access, Arcview (GIS software) ; Maptitude, SaTScan, Centrus
Quality assurance: Re-abstraction of cases, Comparison/verification between multiple data sources, Clinical review, Timeliness, Records linkage and de-duplication
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Environmental Studies

System integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases

Funding
Funding source: 26% General state funds, 30% Service fees, 43% CDC grant

Other
Web site: http://www.cdphe.state.co.us

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Connecticut

Connecticut Birth Defects Registry (CT BDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Reporting for MCH Block Grant
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 2002
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 37,000
Statewide: Yes
Current legislation or rule: Sec. 19a-53. (Formerly Sec. 19-21). Reports of physical defects of children. Sec. 19a-54. (Formerly Sec. 19-21a). Registration of physically handicapped children. Sec. 19a-56a birth defects data. (Formerly Sec. 10a-132b). Birth defects surveillance program. Sec. 19a-56b (formerly Sec. 10a-132d). Confidentiality of birth defects information. Access.

Case Definition

Outcomes covered: All major structural birth defects; biochemical, genetic and hearing impairment through linkage with Newborn Screening System; any condition which places a child at risk for needing specialized medical care (i.e., complications of prematurity, cancer, trauma, etc.) ICD-9 codes 740 thru 759.9 and 760.71. ICD10 codes include the entire Q series as well as some recommended by CDC in the provided crosswalk.
Pregnancy outcome: Livebirths (All gestational ages and birth weights, PDA = to 2500 gms birth weight)
Age: Up to one year after delivery for birth defects, but reported up to age 5
Residence: All in-state births are reported but reporting is cone on in-state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation, microcephaly is currently rapid assertainment (within 12 hours of birth) and referred to the CT DPH Infectious Disease program for follow-up.
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, inpatient hospitalizations and emergency room visits
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Developmental Disabilities Surveillance
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Reports from health care professionals in newborn nurseries and NICUs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Reports from health care professionals in pediatric inpatient and outpatient services planned for future
Other sources: Midwifery Facilities, Physician reports, Mandatory reporting by health care providers and facilities; CYSHCN Programs; Newborn Screening System (for genetic disorders and hearing impairment).

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)
Coding: ICD-9-CM, ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Mainframe, Web based database just moved to sequel server

Data Analysis

Data analysis software: SAS, Access, Arc GIS
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Epidemiologic studies (using only program data), Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects, Provider education

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: We are integrated with the newborn metabolic and early hearing and detection intervention. Vital Records imports into the Maven Newborn Screening System (NSS). This database also links with the Lead program and the new Children and Youth with Special Health Care Needs program.

Funding

Funding source: 80% General state funds, 20% MCH funds

Other

Web site: http://www.ct.gov/dph/birthdefectsregistry
Surveillance reports on file: NBDPN annual reports, state profiles

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Delaware

Delaware Birth Defects Registry (DBDR)

Purpose: Surveillance
Partner: Local Health Departments, Hospitals, Early Childhood Prevention Programs, Birthing Centers
Program status: Currently collecting data
Start Year: 2007
Earliest year of available data: 2007
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 12,000
Statewide: Yes
Current legislation or rule: House Bill No. 197, an act to amend Title 16 of the Delaware Code relating to Birth Defects
Legislation year enacted: 1997

Case Definition

Outcomes covered: Selected major birth defects, selected metabolic defects, genetic diseases, and infant morality.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Or greater than 350 grams.)
Age: Birth to 1 year
Residence: In-state births to state resident

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment, Population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Developmental Disabilities Surveillance, Cancer registry, AIDS/HIV registry
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Postmortem/pathology logs, Specialty outpatient clinics, High risk pregnancy logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Postmortem/pathology logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Midwifery Facilities, Physician reports

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, GI condition (e.g. intestinal blockage), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Capture-recapture analyses, Epidemiologic studies (using only program data), Education/public awareness

System integration

System links: Link to other state registries/databases, Link to Newborn Bloodspot and Hearing Screening.

Funding

Funding source: 40% General state funds, 60% MCH funds

Other

Web site: http://dhss.delaware.gov/dhss/dph/chca/dphbdr1.html
Surveillance reports on file: Analysis of the 2007 Delaware Birth Defects Registry http://dhss.delaware.gov/dhss/dph/chca/files/birthdefectsregistryreport2007.pdf

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District of Columbia

Program status: No surveillance program

Surveillance Methods

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

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Florida

Florida Birth Defects Registry (FBDR)

Purpose: Surveillance, Research, Educate health care professionals, women of childbearing age and general public about birth defects.
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Legislators, Federal and state agencies
Program status: Currently collecting data
Start Year: 1998
Earliest year of available data: 1998
Organizational location: Department of Health (Epidemiology/Environment), University
Population covered annually: 211,228 in 2014
Statewide: Yes
Current legislation or rule: Section 381.0031(1,2) F.S., allows for development of a list of reportable conditions. Birth defects were added to the list in July 1999.
Legislation year enacted: 1999

Case Definition

Outcomes covered: Major structural malformations and genetic disorders
Pregnancy outcome: Livebirths (20 week gestation and greater)
Age: Until age 1
Residence: Florida

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation, FL has two CDC funded cooperative agreements which use active case ascertainment which is linked to the passive surveillance program.
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs
Delivery Hospitals: Disease index or discharge index
Pediatric & tertiary care hospitals: Disease index or discharge index

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)
Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Dedicated server for birth defects data

Data Analysis

Data analysis software: SAS, Access, SQL, dBASE
Quality assurance: Validity checks, Re-abstraction of cases, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases, Maternal linked file.
System integration: The department has created a maternally linked file beginning with 1998. The birth defects data has been included in this linked file. Birth defects data are displayed on the department's Environmental Public Health Tracking Program site.

Funding

Funding source: 75% General state funds, 23% CDC grant, 2% Private Foundation
Web site: www.fbdr.org
Surveillance reports on file: Publications, procedure manauals, electronic case ascertaintment dababase and educational materials

Comments: CDC/NCBDDD Cooperative Agreement for enhanced surveillance of selected birth defects, referral for services and prevention activities.

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Georgia

Georgia Birth Defects Reporting And Information System (GBDRIS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 2003
Earliest year of available data: 2007
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health)
Population covered annually: 131,333 in 2015
Statewide: Yes
Current legislation or rule: Birth defects are reportable under State Laws Official Code of Georgia Annotated (OCGA) 31-12-2 and 31-1-3.2 which mandate the reporting of notifiable diseases and newborn hearing screening, and Chapters 290-5-3-.02 and 290-5-24 of the Rules of Department of Human Resources, which regulate the reporting of notifiable diseases and metabolic disorders.

Case Definition
Outcomes covered: NBDPN core and recommended birth defects plus microcephaly.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Up to 18 years of age
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificate
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Disease index or discharge index, Discharge summaries
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked
Coding: ICD-9-CM, ICD-10-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications, Maternal risk factors
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Microsoft SQL Server 2012

Data Analysis
Data analysis software: SAS, Access, Microsoft SQL Server 2012
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Public health program evaluation, Monitoring outbreaks and cluster investigations, Service delivery, Grant proposals
System integration
System integration: We are working to integrate it with our child health data system that contains birth, genetics and intervention referrals.

Funding
Funding source: 100% MCH funds

Other
Additional information on file: In Georgia, please note that other surveillance is performed by Metropolitan Atlanta Congenital Defects Program (MACDP) and that is where the numbers for your report come from.

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Hawaii

Hawaii Birth Defects Program (HBDP)

Purpose: Surveillance
Partner: Hospitals, Iowa Registry for Congenital and Inherited Disorders
Program status: Currently collecting data
Start Year: 1988
Earliest year of available data: 1986
Organizational location: Department of Health (Children with Special Health Needs Branch)
Population covered annually: 19,000
Statewide: Yes
Current legislation or rule: Hawaii Revised Statutes - sec. 321-421 through 426 Hawaii Revised Statutes - sec. 324-41 through 44
Legislation year enacted: 2002

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Less than 20 weeks gestation, 20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: Up to one year after delivery
Residence: All in-state births

Surveillance Methods
Case ascertainment: Active Case Finding
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Ocular conditions, Auditory/hearing conditions, Any infant with a codable def
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Double-checking of assigned codes, Clinical review
Data use and analysis: Epidemiologic studies (using only program data)

Funding
Funding source: 100% State of Hawaii Birth Defects Special Fund
Web site: http://health.hawaii.gov/genetics/programs/hbdhome/

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Idaho

Program status: No surveillance program

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Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Drug-testing laboratories; Departments of Human Services, Health and Family Services, Children and Family Services; Newborn Metabolic Screening Program,
Program status: Currently collecting data
Start Year: 1986
Earliest year of available data: 1989
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 155,000
Statewide: Yes
Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/) 77 Illinois Administrative Code 840

Case Definition

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, or the family chose to hold a funeral)
Age: 2 years
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation, Passive case-finding without case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Discharge summaries, Reporting from all hospital nurseries
Pediatric & tertiary care hospitals: Discharge summaries, Reporting from all hospital nurseries

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All prenatal diagnosed or suspected cases, APORS collects and refers cases of neonatal deaths, infants with gestational age less than 31 weeks, infants with prenatal drug exposure (excluding marijuana), serious congenital infections, endocrine, metabolic and immune disorders, hemoglobinopathies, coagulation defects, leukemia, intrauterine growth restriction, seizures, conditions leading to more than 72 hours on a ventilator, and selected other conditions. Only charts with reported selected birth defects are reviewed.
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Purpose-built system linked with Vital Record System

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Cases are collected in a database that is a module of the Vital Record reporting system. Cases may be initiated from the birth certificate, by hospital staff or by APORS staff. Local community health agencies have access to cases in their jurisdiction for provision of case-management services. APORS cases are also included in the Illinois Healthcare and Family Services Enterprise Data Warehouse where they are available to Illinois' Department of Human Services, Department of Children and Family Services, and Department of Healthcare and Family Services staffs.

Funding

Funding source: 52% General state funds, 42% CDC grant, 6% Other federal funding (non-CDC grants)
Web site: http://www.dph.illinois.gov/data-statistics/epidemiology/apors
Surveillance reports on file: Birth Defects and Other Adverse Pregnancy Outcomes in Illinois 2005-2009 Trends in the Prevalence of Birth Defects in Illinois and Chicago 1989-2009
Additional information on file: QC reports, fact sheets

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Indiana

Indiana Birth Defects & Problems Registry (IBDPR)

Purpose: Surveillance, Research, Referral to Services
Partner: Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 2002
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health, State Health Data Center)
Population covered annually: 85,000
Statewide: Yes
Current legislation or rule: IC 16-38-4-7 Rule 410 IAC 21-3
Legislation year enacted: 2001

Case Definition

Outcomes covered: ICD-9-CM Codes 740-759.9, Fetal Alcohol Spectrum Disorder (760.71), Pervasive Developmental Disorders (299.0-299.99), fetal deaths, metabolic disorders & hearing loss from newborn screening, selected neoplasms, congenital blood disorders, and certain eye disorders.
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Up to 5 years (FAS); all individuals with Autism Spectrum Disorders; up to 3 years for all other birth defects
Residence: In- and out-of-state (as reported to IBDPR) births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation, Passive case-finding without case confirmation, case confirmation for hospital discharge data; w/o case confirmation for physician reporting
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Disease index or discharge index, Chart audits of 49 targeted birth defects
Pediatric & tertiary care hospitals: Disease index or discharge index, Chart audits of 49 targeted birth defects
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM, and BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), ISDH Chart Auditors submit hospital chart audit information electronically through use of a laptop and a web-based portal to the Indiana State Department of Health Repository, which stores and integrates the data.
Database collection and storage: Oracle

Data Analysis

Data analysis software: SAS, Oracle and ArcView GIS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Needs assessment

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: The database is linked with birth, death, newborn hearing screening, and newborn metabolic and pulse oximetry screening data.

Funding

Funding source: 30% MCH funds, 5% Genetic screening revenues, 65% IBDPR fund obtained through birth certificate search

Other

Web site: www.birthdefects.in.gov
Surveillance reports on file: "Progress on the Implementation of IC 16-38-4-7 (Birth Problems Registry) as amended in First Regular Session 112th General Assembly (2001) Reporting Period: July 2014-June 2015" http://www.in.gov/isdh/files/IBDPR_Annual_Report_for_14_15_reporting_period_final_10_30_15.pdf

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Iowa

Iowa Registry for Congenital and Inherited Disorders (IRCID)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Prevention education programs
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Legislators
Program status: Currently collecting data
Start Year: 1983
Earliest year of available data: 1983
Organizational location: University
Population covered annually: 38,813 average live births per year (2009-2013)
Statewide: Yes
Current legislation or rule: Iowa Code 136A, Iowa Administrative Code 641-4.7

Case Definition

Outcomes covered: Major birth defects, muscular dystrophy, fetal deaths with and without birth defects, newborn screening disorders
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: 2 years
Residence: Maternal residence in Iowa at time of delivery

Surveillance Methods

Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Death certificates, Fetal death certificates, Fetal Death Evaluation Protocol
Other state based registries: Programs for children with special needs, Developmental Disabilities Surveillance, Cancer registry, Iowa Perinatal Care Program
Delivery Hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Collect verbatim summaries of surgical reports, diagnostic test results, consultation reports, and autopsy/surgical pathology reports.
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Cardiac catheterization laboratories, Specialty outpatient clinics, Collect verbatim summaries of surgical reports, diagnostic test results, consultation reports, and autopsy/surgical pathology reports.
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities
Other sources: Physician reports, Outpatient surgery facilities; IHA Discharge Data

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Developmental delay, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access, Oracle, PC Server

Data Analysis

Data analysis software: SAS, Access, Oracle
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Capture-recapture analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases

Funding

Funding source: 100% General state funds

Other

Web site: http://www.public-health.uiowa.edu/ircid/

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Kansas

Kansas Birth Defects Information System (BDIS)

Purpose: Surveillance
Partner: Hospitals, Environmental Agencies/Organizations, Universities
Program status: Interested in developing a surveillance program
Start Year: 1985
Earliest year of available data: 1985
Organizational location: Department of Health (Epidemiology/Environment, Maternal and Child Health, Vital Statistics)
Population covered annually: 39,193
Statewide: Yes
Current legislation or rule: K.S.A. 65-1,241 through 65-1,246
Legislation year enacted: 2004

Case Definition

Outcomes covered: The outcome data below are available from Office of Vital Statistics. Live births and stillbirths (fetal deaths) information are used as part of the Birth Defects Information System (BDIS). Thirteen anomalies (and "other" congenital anomalies) are listed on the birth certificate and are reported, however, these are not linked to ICD-9 codes. In addition to major birth defects, low birth weight (<=1,200 grams), low Apgar scores (<=5 at five minutes), seizure or serious neurologic dysfunction, and significant birth injury [skeletal fracture(s), peripheral nerve injury, and/or soft tissue/solid organ hemorrhage which requires intervention] are also reported to BDIS.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Under five years of age with a primary diagnosis of a congenital anomaly or abnormal condition
Residence: In state and out of state births to Kansas residents and in-state births to out of state residents

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates, Stillbirth (fetal death) certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Reports
Pediatric & tertiary care hospitals: Reports
Other sources: Physician reports

Case Ascertainment

Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), In Kansas, birth defects (congenital anomalies) are collected through three data sources: live birth certificates, stillbirth (fetal death) certificates, and the congenital malformations and fetal alcohol syndrome reporting form. The live birth and stillbirth (fetal death) certificates data (congenital anomalies and abnormal conditions) contained within the Vital Statistics Integrated Information System are extracted, downloaded and transferred to BDIS. Any additional reports of congenital anomalies from physicians, hospitals and freestanding birthing centers are entered manually into BDIS.
Database collection and storage: Access, SQL Server

Data Analysis

Data analysis software: SAS
Quality assurance: Office of Vital Statistics conducts verification on live birth and stillbirth (fetal death) certificate data.
Data use and analysis: Baseline rates, Rates by demographic and other variables, Time trends, Grant proposals, Ad-hoc upon request (e.g. cluster investigations)

System integration

System links: Link to other state registries/databases
System integration: Our program has a link with vital statistics records. BDIS uses the same data system (WebBFH) and shares information with Children and Youth with Special Health Care Needs and Newborn metabolic screening program.

Funding

Funding source: 100% MCH funds

Other

Web site: http://www.kdheks.gov/bfh/birth_defects.htm

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Kentucky

Kentucky Birth Surveillance Registry (KBSR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Genetic Clinics, Laboratories,
Program status: Currently collecting data
Start Year: 1998
Earliest year of available data: 1998
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 56,000
Statewide: Yes
Current legislation or rule: Kentucky Revised Statute 211.660 Kentucky birth surveillance registry - Department's authority to promulgate administrative regulations. Effective: July 15, 2002
Legislation year enacted: 2002

Case Definition

Outcomes covered: KBSR collects information concerning birth defects, stillbirths, and high-risk conditions for Kentucky residents birth to age five. Diagnoses include the following ICD-9 codes: • All congenital anomalies codes - 740-759 • Dwarfism not elsewhere classified - 259.4. • Metabolic/storage disorders - 270-279, Excluding codes 274, 276 and 278. • Hereditary hemolytic anemia - 282. • Neurologic disorders of brain and spinal cord - 334-335. • Cerebral palsy - 343. • Teratogens (noxious influences) - 760.7 and all subcategories, from 760.70 to 760.79. • Infant of diabetic mother - 775.0. • Failure to thrive - 783.4. • Small for gestational age - 764.0 • Neonatal Abstinence Syndrome – 760.79 • Fetal Alcohol Syndrome – 760.71
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (A fetal death of twenty (20) completed weeks' gestation or more, calculated from the date last normal menstrual period began to the date of deliv
Age: Up to 5 years of age
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Newborn CCHD Screening
Delivery Hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Laboratory logs, Specialty outpatient clinics
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM, ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Online database developed in-house

Data Analysis

Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiologic studies (using only program data), Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Birth records from vitals statistics are linked with all cases in the KBSR database. Data from the state Newborn CCHD Screening database and the state Neonatal Abstinence Syndrome surveillance system are incorporated into KBSR.

Funding

Funding source: 100% CDC grant
Web site: http://chfs.ky.gov/dph/mch/ecd/kbsr.htm
Surveillance reports on file: Birth Defect Specific Fact Sheets; Contact of Partners

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Louisiana

Louisiana Birth Defects Monitoring Network (LBDMN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 2005
Earliest year of available data: 2005
Organizational location: Department of Health (LDH/OPH/CCPH/BFH/Title V CYSHCN Programs)
Population covered annually: 62,000
Statewide: Yes
Current legislation or rule: Law: LA R.S. 40:31.41 - 40:31.48, 2001. DHH Rule: LAC 48:V. Chapters 161 and 163
Legislation year enacted: 2001

Case Definition

Outcomes covered: Major structural birth defects and selected genetic conditions
Pregnancy outcome: Livebirths (greater than or equal to 20 weeks gestation or greater than or equal to 350 grams)
Age: Up to third date of birth
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Active Case Finding, Combination of active and passive case ascertainment, population based
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Delivery Hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Other sources: Louisiana Hospital Inpatient Discharge Data (LAHIDD)

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any chart with selected ICD-10 Q codes, N13.1-N13.4; E78.71-E78.72.

Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM, ICD-10

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Custom built web-based database.

Data Analysis

Data analysis software: SAS, ArcGIS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link case finding data to final birth file, Link case finding data to final death file
System integration: Integrated with Louisiana Electronic Event Registration System (LEERS) birth and death records.

Funding

Funding source: MCH Title V Block Grant State Matching Funds

Other

Web site: www.dhh.la.gov/lbdmn
Surveillance reports on file: Louisiana Morbidity Report, May-June 2009, Vol 20, No 3; Results from 2006-2008 Birth Defects Surveillance System; 2013 Annual NBDPN Data Report; Presentations of analysis using 2006-2008 data concerning ASD Reporting; Cleft Lip/Palate and Hearing Loss; and Age and Racial Disparities.
Additional information on file: Advisory Board Documentation http://wwwprd.doa.louisiana.gov/boardsandcommissions/viewBoard.cfm?board=192

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Maine

Maine CDC Birth Defects Program (MBDP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Education
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, March of Dimes, New England Birth Defects Consortium, Maine Tracking Network
Program status: Currently collecting data
Start Year: 1999
Earliest year of available data: 2003
Organizational location: Department of Health (Division of Population Health/MCH Unit/CSHN)
Population covered annually: 12,593
Statewide: Yes
Current legislation or rule: 22 MRSA c. 1687
Legislation year enacted: 1999

Case Definition
Outcomes covered: Selected major birth defects: NTD, clefts, gastroschisis, omphalocele, trisomy 21, reduction deformities of upper and lower limb, hypospadias and major heart defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Less than 20 weeks gestation, 20 weeks gestation and greater, Prenatally diagnosed at any gestation), Elective terminations (Prenatally diagnosed
Age: Through age one
Residence: All in-state births to Maine residents

Surveillance Methods
Case ascertainment: Passive case ascertainment with active case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities
Other sources: Midwifery Facilities, Physician reports, Children with Special Health Needs

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, ICD-10 codes
Conditions warranting chart review beyond the newborn period: Cardiovascular condition, Any infant with a codable defect
Coding: ICD-9-CM, ICD-10 codes

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic scanning of printed records
Database collection and storage: Oracle, Microsoft SQL Server

Data Analysis
Data analysis software: SAS, Stat-exact
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: Newborn Hearing/ Newborn Bloodspot Screening Programs

Funding
Funding source: 100% MCH funds

Other
Web site: http://www.maine.gov/dhhs/boh/cshn/birth_defects/index.html

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Maryland

Maryland Birth Defects Reporting and Information System (BDRIS)

Purpose: Surveillance, Referral to Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 1983
Earliest year of available data: 1984
Organizational location: Department of Health (Epidemiology/Environment, Prevention and Health Promotion Administration)
Population covered annually: 75,000
Statewide: Yes
Current legislation or rule: Health-General Article, Section 18-206; Annotated Code of Maryland
Legislation year enacted: 1982

Case Definition

Outcomes covered: Selected birth defects - anencephaly, spina bifida, hydrocephaly, cleft lip, cleft palate, esophageal atresia/stenosis, rectal/anal atresia, hypospadias, reduction deformity - upper or lower limb, congenital hip dislocation, and Down syndrome until 2009, then all significant birth defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights,), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Or >=500 grams weight; reports accepted on fetal deaths <500 grams or <20 weeks gestation if sent to us.), Ele
Age: Newborn
Residence: All in-state births

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Sickle Cell Disease, Critical Congenital Heart Defect follow Up Program
Delivery Hospitals: Primary source: sentinel birth defects hospital report form; electronic reporting began 5/1/13
Pediatric & tertiary care hospitals: transfers from delivery hospitals, if screening not done at delivery hospital.
Other sources: Midwifery Facilities

Case Ascertainment

Conditions warranting chart review in the newborn period: All fetal death certificates
Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access, Mainframe, Visual dBASE, SAS, ASCII files; as of 5/1/13 data stored on vendor server

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Identification of potential cases for other epidemiologic studies, Service delivery, Referral, Grant proposals, Education/public awareness

System integration

System integration: As of 5/1/13, the birth defects data collection is integrated into the same electronic system in which we collect hearing and CCHD screening data.

Funding

Funding source: 100% General state funds

Other

Web site: http://phpa.dhmh.maryland.gov/genetics/SitePages/bdris.aspx
Surveillance reports on file: All reports submitted to CDC

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Massachusetts

Massachusetts Birth Defects Monitoring Program (MBDMP)

Purpose: Surveillance, Research, Public health program evaluation, assist community health assessments
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Maternal and Child Health Programs, State Lab
Program status: Currently collecting data
Start Year: 1997
Earliest year of available data: 1999
Organizational location: Department of Public Health (Bureau of Family Health and Nutrition)
Population covered annually: 73,000
Statewide: Yes
Current legislation or rule: Massachusetts General Laws, Chapter 111, Section 67E in 1963. In 2002 the Massachusetts legislature amended this statute, expanding the birth defects monitoring program. In 2009 regulations for a Congenital Anomalies Registry, 105 CMR 302.000, were promulgated.

Case Definition

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (>= 20 weeks gestation or >= 350 grams), Unspecified non-live births (Includes elective terminations at all gestational ages and spontaneous losses <20 weeks and <350 grams).
Age: 1 year
Residence: In- and out-of-state births to state residents

Surveillance Methods

Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal death certificate
Delivery Hospitals: Disease index or discharge index, Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Postmortem/pathology logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All prenatal diagnosed or suspected cases, Any birth certificate with a major birth defect box checked
Conditions warranting chart review beyond the newborn period: All infant deaths (excluding prematurity), Any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access

Data Analysis

Data analysis software: SAS, Access, Excel
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Epidemiologic studies (using program data)

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link case finding data to open and closed birth file, as well as open and closed fetal file.
System integration: Link birth defects data to Pregnancy to Early Life Longitudinal (PELL) data system.

Funding

Funding source: 40% General state funds, 60% MCH funds
Web site: www.mass.gov/dph/birthdefects
Surveillance reports on file: Annual or bi-annual reports, 1999 through 2012

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Michigan

Michigan Birth Defects Registry (MBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Prevalence and mortality statistics
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators, Outpatient Pediatrics clinics for HL7 reporting pilot
Program status: Currently collecting data
Start Year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Vital Statistics)
Population covered annually: 112,000
Statewide: Yes
Current legislation or rule: Public Act 236 of 1988
Legislation year enacted: 1988

Case Definition

Outcomes covered: Congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks or >400 grams)
Age: Up to two years after delivery except that reporting to age 12 for FASD beginning in 2013
Residence: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, Fetal deaths since 2004 only
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry
Delivery Hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Physician reports, Pediatric Dentistry

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood death
Coding: ICD-9-CM, ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: FoxPro

Data Analysis

Data analysis software: SPSS, SAS, Access, Fox-pro, Excel
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file, CSHCS, WIC
System integration: No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

Funding

Funding source: 10% CDC grant

Other

Web site: http://www.michigan.gov/mdch/0,1607,7-132-2944_4670---,00.html
Additional information on file:
Http://www.michigan.gov/mdch/0,1607,7-132-2945_5221-16665--,00.html

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Minnesota

Minnesota Birth Defects Information System (BDIS)

Purpose: Surveillance, Research, Referral to Services, Targeted prevention to higher risk populations.
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start Year: 2005
Earliest year of available data: 2006
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 70,000
Statewide: No, Currently covering about 95% of live births in MN. Statewide surveillance is expected to be completed by the end of 2016. Coverage is complete for smaller regions of the state. Prevalence estimates from 2006-2010 are available for the two largest counties in Minnesota, Hennepin and Ramsey counties, which account for just over 40% of MN births. For 2011 births, coverage expanded to complete in the 7-county metro area.
Current legislation or rule: MS 144.2215-2219
Legislation year enacted: 2004

Case Definition
Outcomes covered: Major structural and genetic defects diagnosed up to 1 year of age identified by CDC and NBDPN.
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Up to 1 year after delivery
Residence: In-state and out of state births to state residents

Surveillance Methods
Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics
Third party payers: In 2017, Medicaid databases will become available.
Other sources: Statewide de-identified hospital discharge dataset

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any birth certificate with a birth defect box checked, All deaths prior to age 2 with a birth defect indicated as cause of death on death certificates, starting with 2009 births
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Family history

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Remote access to medical records in two health systems and five facilities as of May 20016
Database collection and storage: Web-based department-wide integrated disease surveillance database. Maven platform by Consilience Software.

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Identification of potential cases for other epidemiologic studies, Needs assessment, Referral, Education/public awareness, Prevention projects, Collaboration with Environmental Public Health Tracking Program

System integration
System links: Link to other state registries/databases, Link case finding data to final birth file, Sharing of confirmed cases with key contacts at local public health agencies for service referral. LPH staff can log on to our the birth defects database to view relevan
System integration: The Birth Defects Information System (BDIS) is integrated with Newborn Hearing program and Heritable Conditions. The databases share a model on the same platform, but they are managed separately. (This platform, Maven by Consilience Software, is also used by many infectious disease surveillance systems in MN and access is limited by disease/user role.) Additional integration with the Newborn Screening program will take place in 2014 as universal newborn CCHD screening is implemented.

Funding
Funding source: 90% General state funds, 10% CDC grant

Other
Web site:
http://www.health.state.mn.us/divs/cfh/program/cyshn/bdmaintro.cfm

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Mississippi

Mississippi Birth Defects Surveillance Registry

Purpose: Surveillance
Partner: Local Health Departments, Hospitals, Advocacy Groups, Title V Children with Special Healthcare Needs
Program status: Currently collecting data
Start Year: 2000
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health, Genetic Services Bureau)
Population covered annually: 38,000
Statewide: Yes
Current legislation or rule: Section 41-21-205 of the Mississippi Code of 1972
Legislation year enacted: 1997

Case Definition
Outcomes covered: The infant/fetus must have a reportable structural defect, newborn screening disorder, functional or metabolic disorder, genetically determined or a defect resulting from an environmental influence during embryonic or fetal life.
Pregnancy outcome: Livebirths, Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Birth to 21 years
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation, Active case-finding for Zika related birth defects
Vital Records: Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in the newborn period: Zika related birth defects
Coding: ICD 10

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, New web based program (in development)

Data Analysis
Data analysis software: SPSS, SAS, Access
Quality assurance: Validity checks, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiologic studies (using only program data), Grant proposals, Education/public awareness

System integration
System links: Link case finding data to final birth file, Newborn Screening Program Newborn screening program database and Early Hearing program database

Funding
Funding source: 100% Genetic screening revenues

Other
Web site: www.HealthyMS.com

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Missouri

Missouri Birth Defects Surveillance System

Purpose: Surveillance, Research
Partner: Environmental Agencies/Organizations, Legislators, Missouri Critical Congenital Heart Defect testing program
Program status: Currently collecting data
Start Year: 1985
Earliest year of available data: 1980
Organizational location: Department of Health (Vital Statistics)
Population covered annually: '76000
Statewide: Yes

Case Definition
Outcomes covered: ICD-9 codes 740-759, plus genetic, metabolic, and other disorders
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, Fetal death certificates are only source of data)
Age: Up to one year after delivery
Residence: In- and out-of-state births to state residents

Surveillance Methods
Case ascertainment: Population-based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Delivery Hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics

Case Ascertainment
Conditions warranting chart review in the newborn period: Missouri does not have resources to conduct confirmatory chart review for cases.
Coding: ICD-9-CM, ICD-10-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: SAS

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Education/public awareness

System integration
System links: Link case finding data to final birth file

Funding
Funding source: 100% MCH funds
Web site: http://health.mo.gov/data/birthdefectsregistry/index.php
Surveillance reports on file: MO Birth Defects Report 1996-2000

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Montana

Montana Birth Outcomes Monitoring System (MBOMS)

Program status: No surveillance program
Start Year: 1999
Earliest year of available data: 2000
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 12,000
Current legislation or rule: None

Case Definition

Outcomes covered: Major structural birth defects, chromosomal anomalies specified in the CDC 45 reportables for births occurring in calendar years 200 through 2004. Registry suspended beginning with calendar year 2005 births due to loss of CDC funding.
Pregnancy outcome: Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages)

Comments: MBOMS became inactive in 2005

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Nebraska

Nebraska Birth Defect Registry

Purpose: Surveillance, Research
Partner: Hospitals, Universities, Early Childhood Prevention Programs, Vital Statistics, Maternal Child Health
Program status: Currently collecting data
Start Year: 1972
Earliest year of available data: 1973
Organizational location: Department of Health (Vital Statistics, Office of Epidemiology and Informatics)
Population covered annually: 27,000
Statewide: Yes
Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health & Welfare [Codes] §71-645, §71-646, §71-647, §71-648, §71-649)
Legislation year enacted: 1972

Case Definition
Pregnancy outcome: Livebirths (=> 20 weeks, => 500 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (=> 20 weeks, => 500 grams)
Age: Up to one year after delivery
Residence: In state birth to state resident, out of state births to state residents when Out State Jurisdiction allows use of data

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates, Death certificates, Fetal death certificate
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Midwifery Facilities, Physician reports

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any birth certificate with a birth defect box checked
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: SQL

Data Analysis
Data analysis software: SAS, Reports from Netsmart
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Grant proposals

System integration
System links: Link to other state registries/databases
System integration: Births, Deaths, Fetal deaths

Funding
Funding source: 100% MCH funds

Other
Web site:
http://dhhs.ne.gov/publichealth/Pages/vitalrecords_partners.aspx
Surveillance reports on file:
Http://dhhs.ne.gov/publichealth/Pages/ced_vs.aspx

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Nevada

Nevada Birth Outcomes Monitoring System (NBOMS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Hospitals, Early Childhood Prevention Programs, Legislators, Bureau of Child, Family, & Community Wellness
Program status: Currently collecting data
Start Year: 2000
Earliest year of available data: 2005
Organizational location: Department of Health (Maternal and Child Health), State Health Division, Office of Health Statistics and Surveillance, Bureau of Health Statistics, Planning, Epidemiology and Response
Population covered annually: 35,000
Statewide: Yes
Current legislation or rule: NRS 442.300 - 442.330 - Birth Defects Registry Legislation *** Regulation = NAC 442
Legislation year enacted: 1999

Case Definition

Outcomes covered: Major birth defects and genetic diseases
Pregnancy outcome: Livebirths (20 weeks of gestation and greater with all birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (20 weeks gestation and greater)
Age: Birth to 7 years of age
Residence: In-state births

Surveillance Methods

Case ascertainment: 2011-2013 data combination of active & passive, Population-based, Hospital-based. 2014 and subsequent data passive data collection (hospital discharge data).
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, hospital medical records, diagnostic/laboratory reports
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Cancer registry, AIDS/HIV registry
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other specialty facilities: Genetic counseling/clinic genetic facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any birth certificate with a birth defect box checked
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Developmental delay, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Any infant with a codable defect
Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff
Database collection and storage: Access

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link to other state registries/databases, Birth registry data is manually linked to birth defect data, but the actual databases are not linked.
System integration: No

Funding

Funding source: 100% MCH Block Grant, (Office of Public Health Informatics and Epidemiology (OPHIE) provides the statistician for data workup

Other

Surveillance reports on file:
Http://dpbh.nv.gov/Programs/NBOMS/dta/Publications/Nevada_Birth_Outcomes_Monitoring_System_%28NBOMS%29_-_Publications/

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New Hampshire

New Hampshire Zika Birth Conditions Program

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Program status: Program has not started collecting data
Organizational location: Department of Health (Maternal and Child Health), University
Population covered annually: 12,500
Statewide: Yes
Current legislation or rule: RSA 141:J, NH Administrative Rules He-P 3012
Legislation year enacted: 2008

Case Definition
Outcomes covered: Will be determined prior to program's initiation.

Surveillance Methods
Case ascertainment: Will be determined prior to program's initiation.

Funding
Funding source: 100% CDC grant

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New Jersey

Special Child Health Services Registry (SCHS Registry)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Legislators, Neurodevelopmental Centers; Federally Qualified Health Care Centers; State Parent Advocacy Network
Program status: Currently collecting data
Start Year: 1928
Earliest year of available data: 1985
Organizational location: Department of Health (Special Child Health and Early Intervention Services)
Population covered annually: 105,000
Statewide: Yes
Current legislation or rule: NJSA 26:8-40.2 et seq., NJAC 8:20 - Ammended: 1990, 1991, 1992, 2005, Readopted: 2010, Rule Amendments Adopted: 2009; Readopted: 2010
Legislation year enacted: 1983

Case Definition
Outcomes covered: All birth defects (structural, genetic, and biochemical), all Autism Spectrum Disorders, and severe hyperbillirubinemia, are required to be reported; all special needs and any condition which places a child at risk (prematurity, asthma, developmental delay) are also reported, but not required.
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Mandated reporting of birth defects diagnosed through age 5, voluntary reporting of birth defects diagnosed > age 6 and all children diagnosed with Special Needs conditions who are 22 years or younger . Autism mandated up to 22 years.
Residence: All NJ residents, in and out of state

Surveillance Methods
Case ascertainment: combination of active & passive, Population-based, with annual audits
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Autism Registry
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Specialty outpatient clinics, Quality assurance visit consisting of chart review of 3 month period
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Laboratory logs, Specialty outpatient clinics, quality assurance visit consisting of chart review of 3 month period
Third party payers: Universal billing database is used for quality assurance activities
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Midwifery Facilities, Physician reports, Special Child Health Services county-based Case Management Units, parents, medical examiners, Autism diagnosticians and treatment centers

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, All neonatal deaths, All death certificates for < 3 years of age
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect
Coding: ICD-9-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Mainframe, SAS; SQL

Data Analysis
Data analysis software: SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness, Merge registry with birth certificate registry and the death certificate registry
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration
System links: Link to other state registries/databases, Link case finding data to final birth file, link to hearing screening registry
System integration: Autism Registry is fully integrated. Newborns having failed Pulse Oximetry Screening are integrated with Registry. Newborn hearing screening registry provides direct report to the SCHS Registry. Metabolic screening program provides direct report to SCHS Registry. Autism Registry is included in the Registry. Special Child Health Services county-based Case Management Referral System is included in the Registry.

Funding
Funding source: 90% MCH funds, 10% CDC grant

Other
Web site: http://www.nj.gov/health/fhs/sch/index.shtml

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New Mexico

New Mexico Birth Defects Prevention and Surveillance System (NM BDPASS)

Purpose: Surveillance, Referral to Prevention/Intervention Services
Partner: Hospitals
Program status: Currently collecting data
Start Year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 28,000
Statewide: Yes
Current legislation or rule: In January 2000, birth defects became a reportable condition. These conditions must be reported to the New Mexico Department of Health's Epidemiology and Response Division. Specifically, the conditions must be reported to the Environmental Health Epidemiology Bureau.
Legislation year enacted: 2000

Case Definition

Outcomes covered: 740.0-760.01, with emphasis on 12 birth defects that are nationally consistent data and measures for the Environmental Public Health Tracking Program.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc., Elective terminations (All gestational ages)
Age: Birth through age 4
Residence: Births to New Mexico residents occurring in New Mexico.

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation for selected defects
Vital Records: Birth certificates, Death certificates, Fetal birth certificate
Delivery Hospitals: Birthing hospital reports
Pediatric & tertiary care hospitals: specialty outpatient clinics, including neurosurgery, plastic surgery, pediatric surgical specialists, prenatal diagnostic providers
Third party payers: Children's Medical Services
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities

Case Ascertainment

Conditions warranting chart review in the newborn period:
Cardiovascular conditions, renal agenesis/hypoplasia partial & bilateral
Conditions warranting chart review beyond the newborn period:
Cardiovascular condition
Coding: CDC coding system based on BPA, ICD-9-CM, ICD-10-CM for deaths

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Stata, version 12.1

Data Analysis

Data analysis software: Stata version 12.1
Quality assurance: Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Rates by demographic and other variables

Funding

Funding source: 100% CDC grant
Web site:
https://nmtracking.org/en/health_effects/birthdefects/about_birthdefects/

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New York

New York State Congenital Malformations Registry (CMR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Community outreach and education
Partner: Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start Year: 1982
Earliest year of available data: 1983
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 240,000
Statewide: Yes
Current legislation or rule: Public Health Law Article 2, Title II, Section 225(5)(t) and Article 2, Title I, Section 206(1)(j): Codes, Rules and Regulations, Chapter 1, State Sanitary Code, Part 22.3
Legislation year enacted: 1982

Case Definition

Outcomes covered: Major structural, functional or biochemical abnormality determined genetically or induced during gestation. A detailed list is available upon request.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages, Authority to collect birth defects diagnosed during pregnancy as of 5/25/16)
Age: As of 5/25/16: 10 years for heart defects, muscular dystrophy, genetic conditions, FAS; 2 years for all other defects
Residence: In-state and out-of-state births to state residents; in-state births to non-residents; all children born in or residing in New York

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment; population-based
Other state based registries: NYS Dept. of Health statewide hospital discharge database
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, In regions where active surveillance is conducted.
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics, in regions where active surveillance is conducted.
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, All stillborn infants, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA, ICD-9-CM prior to 1992; both ICD-9-CM and ICD-10-CM from August 2014 onward

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Oracle

Data Analysis

Data analysis software: SAS, Access, JAVA
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness

System integration

System links: Link case finding data to final birth file, Link to environmental databases

Funding

Funding source: 13.6% General state funds, 10.2% MCH funds, 3.4% Genetic screening revenues, 50.2% CDC grant, 13.3% Other federal funding (non-CDC grants), 10% State Superfund
Web site: http://www.health.ny.gov/birthdefects
Surveillance reports on file: Reports for 1983 - 2008 births

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North Carolina

N.C. Birth Defects Monitoring Program (NCBDMP)

Purpose: Surveillance, Research
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Communicable disease programs; State Laboratory for Public Health
Program status: Currently collecting data
Start Year: 1987
Earliest year of available data: 1989
Organizational location: Department of Health (State Center for Health Statistics)
Population covered annually: 120,000
Statewide: Yes
Current legislation or rule: NCGS 130A-131
Legislation year enacted: 1995

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: 1 year
Residence: NC resident births, including out of state deliveries

Surveillance Methods
Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Death certificates, Fetal birth certificate
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics,
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Positive pulse oximetry screening database

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected procedure codes, Any birth certificate with a birth defect box checked, All stillborn infants, All prenatal diagnosed or suspected cases, Failed newborn pulse oximetry screen
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access

Data Analysis
Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Education/public awareness, Prevention projects

System integration
System links: Link case finding data to final birth file, Link to environmental databases, Early Intervention Program

Funding
Funding source: 90% General state funds, 10% MCH funds

Other
Web site: http://www.schs.state.nc.us/units/bdmp/

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North Dakota

North Dakota Birth Defects Monitoring System (NDBDMS)

Purpose: Surveillance
Partner: Advocacy Groups, Universities, The North Dakota Department of Human Services
Program status: Currently collecting data
Start Year: 2002
Earliest year of available data: 1994
Organizational location: Department of Health (Maternal and Child Health, Vital Statistics, Division of Children's Special Health Services)
Population covered annually: 11,265-This data is for CY 2015.
Statewide: Yes
Current legislation or rule: North Dakota Century Code: 1. 23-41-04. Birth report of child with special health care needs made to department. Within three days after the birth in this state of a child born with a visible congenital deformity, the licensed maternity hospital or home in which the child was born, or the legally qualified physician or other person in attendance at the birth of the child outside of a maternity hospital, shall furnish the department a report concerning the child with the information required by the department. 2. 23-41-05. Birth report of child with special health care needs - Use - Confidential. The information contained in the report furnished to the department under section 23-39-04 concerning a child with a visible congenital deformity may be used by the department for the care and treatment of the child pursuant to this chapter. The report is confidential and is solely for the use of the department in the performance of its duties. The report is not open to public inspection nor considered a public record.
Legislation year enacted: 1941

Case Definition
Pregnancy outcome: Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: 12 months or within the year of birth.
Residence: In-state birth/s to state resident.

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Programs for children with special needs
Pediatric & tertiary care hospitals: Specialty outpatient clinics
Third party payers: Medicaid databases
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked
Coding: ICD-9-CM, ICD-10-CM

Data Collected
Infant/fetus: Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Mainframe, Excel and SPSS

Data Analysis
Data analysis software: SPSS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

System integration
System integration: No.

Funding
Funding source: 100% State System Development Initiative (SSDI)

Other
Web site: http://www.ndhealth.gov/cshs/
Surveillance reports on file: North Dakota Birth Defects Monitoring System Summary Report 2001-2005 North Dakota Birth Defects Monitoring System Summary Report 1995-1999

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Ohio

Ohio Connections for Children with Special Needs (OCCSN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Ohio Collaborative to Prevent Infant Mortality, ODH Office of Health Preparedness
Program status: Currently collecting data
Start Year: 2006
Earliest year of available data: 2008
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 140,000
Statewide: Yes
Current legislation or rule: Ohio Revised Code (ORC) 3705.30-3705.36 authorizes the department to implement a statewide birth defects information system and mandates hospital reporting (2000). Ohio Administrative Code (OAC) 3701-57-01 to 3701-57-04 specifies conditions to be reported and methods for reporting (2010).
Legislation year enacted: 2000

Case Definition

Outcomes covered: Major congenital anomalies recommended by NBDPN and Ohio stakeholders
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Up to 5 years of age
Residence: Ohio resident children up to 5 years of age

Surveillance Methods

Case ascertainment: Active Case Finding, Passive case-finding with case confirmation, Passive case-finding without case confirmation, Active case finding for microcephaly, hydrocephaly, arthrogryposis, and brain reduction abnormalities; Passive case-finding with diagnostic v
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn screening for CCHD data system - electronic birth certificate system
Delivery Hospitals: Hospital medical records and other electronic administrative data sets
Pediatric & tertiary care hospitals: Discharge summaries, Laboratory logs, Hospital medical records and other electronic administrative data sets
Other sources: Genetics Clinic Data within some hospitals

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, ICD-9 and ICD-10 (death certificates) or named congenital anomaly
Coding: ICD-9-CM, ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.), Hospital reporters upload file to secure website for integration. Small volume hospitals can manually key data into secure user interface.
Database collection and storage: SQL server. External system data methods and storage: ODBC connection with SAS. SAS import of other data sets and merge export of cohort line lists to MS Excel for follow-up.

Data Analysis

Data analysis software: SPSS, SAS, MS Excel
Quality assurance: Validity checks, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Observed vs. expected analyses, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link to other state registries/databases, OCCSN data system shares common demographic file with Vital Statistics and Genetics Program data systems.

Funding

Funding source: 100% MCH funds

Other

Web site:
http://www.odh.ohio.gov/odhprograms/cmh/bdefects/birthdefects1.aspx
Surveillance reports on file: 2012 Annual Report

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Oklahoma

Oklahoma Birth Defect Registry (OBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Data used to educate public in the Oklahoma initiative to reduce Infant Mortality
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 1992
Organizational location: Department of Health (Screening and Special Services)
Population covered annually: 52,000
Statewide: Yes
Current legislation or rule: 63 - 1-550.2
Legislation year enacted: 1992

Case Definition

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: 3 years after delivery
Residence: Oklahoma

Surveillance Methods

Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Medical Examiner's autopsy reports
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Discharge summaries, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.)
Other sources: MFM/Neonatology Case Conference

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All neonatal deaths, All elective abortions, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Maternal risk factors, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff
Database collection and storage: Access

Data Analysis

Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Needs assessment, Service delivery, Referral, Education/public awareness, Prevention projects

System integration

System links: Link case finding data to final birth file

Funding

Funding source: 64% MCH funds, 36% CDC grant

Other

Web site:
http://www.ok.gov/health/Child_and_Family_Health/Screening,_and_Special_Services/Oklahoma_Birth_Defects_Registry_/
Surveillance reports on file: Yes

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Oregon

Oregon Birth Anomalies Surveillance System (BASS)

Purpose: Surveillance
Partner: Hospitals, Advocacy Groups, Universities
Program status: Currently collecting data
Start Year: 2013
Earliest year of available data: 2008
Organizational location: Department of Health (Maternal and Child Health Section, Center for Prevention and Health Promotion, Oregon Public Health Division, Oregon Health Authority)
Population covered annually: 45,000
Statewide: Yes
Current legislation or rule: None

Case Definition
Outcomes covered: EPHT-12 and NBDPN 12 core anomalies for surveillance and microcephaly cases.
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: 5 years
Residence: Oregon resident births (in and out-of-state)

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates
Delivery Hospitals: Hospital Discharge Data
Pediatric & tertiary care hospitals: Hospital Discharge Data
Third party payers: Medicaid databases

Case Ascertainment
Coding: lCD-9-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Administrative data sets: Birth Certificate, Hospital Discharge Data and Medicaid claims
Database collection and storage: Access

Data Analysis
Data analysis software: SPSS, Access, Link plus
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Observed vs. expected analyses, Epidemiologic studies (using only program data), Education/public awareness

System integration
System links: Oregon Environmental Public Health Tracking System

Funding
Funding source: 100% Title V funds

Other
Web site:
http://public.health.oregon.gov/HealthyPeopleFfamilies/DataReports/Pages/birth-anomalies.aspx

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Pennsylvania

Pennsylvania Birth Defects Surveillance Database (BDSS)

Program status: No surveillance program

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Puerto Rico

Puerto Rico Birth Defects Surveillance and Prevention System (PRBDSS)

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs
Program status: Currently collecting data
Start Year: 1995
Earliest year of available data: 1995
Organizational location: Department of Health (Services for Children with Special Medical Needs Division)
Population covered annually: 38,000
Statewide: Yes
Current legislation or rule: Law #351
Legislation year enacted: 38246

Case Definition
Outcomes covered: Selected birth defects covered: Neural Tube defects, microcephaly, holoprocencephaly, cleft lip and/or cleft palate, anotia, microtia, anophthalmia, microphthalmia, limb defects, talipes equinovarus, gastrochisis, omphalocele, craneosinostosis, Trisomy 13, 18 and 21, Truner's syndrome, 22q11.2 deletion syndrome, Albinism, Jarcho-Levin syndrome, Prader Willi syndrome, major congenital heart defects, ambiguous genitalia, Hypospadias , and bladder extrophy.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)
Age: Up to 6 years after delivery
Residence: In-state births to state residents

Surveillance Methods
Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Death certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs
Third party payers: Medicaid databases, Health Maintenance organizations (HMOs)
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Cardiovascular condition
Coding: ICD-9-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Prenatal diagnostic information
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access

Data Analysis
Data analysis software: SPSS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

Funding
Funding source: 68% MCH funds, 32% CDC grant

Other
Web site:
http://www.salud.gov.pr/Programas/CampanaAcidoFolico/Pages/default.aspx
Surveillance reports on file: Puerto Rico Birth Defects Annual Report 2012 and 2010

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Rhode Island

Rhode Island Birth Defects Program

Purpose: Surveillance, Referral to Services, Referral to Prevention/Intervention Services
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs, Families
Program status: Currently collecting data
Start Year: 2000
Earliest year of available data: 2002
Organizational location: Department of Health (Center for Health Data and Analysis)
Population covered annually: 10,800
Statewide: Yes
Current legislation or rule: Title 23, Chapter 13.3 of Rhode Island General Laws requires the development of a birth defects surveillance, reporting, and information system that will a) describe the occurrence of birth defects in children up to age five; b) detect trends of morbidity and mortality; and c) identify newborns and children with birth defects to intervene on a timely basis for treatment.
Legislation year enacted: 2003

Case Definition
Outcomes covered: All birth defects and genetic diseases
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Birth up to 5 years
Residence: RI maternal residence

Surveillance Methods
Case ascertainment: Combination of active and passive case ascertainment
Vital Records: Birth certificates, Death certificates, Matched birth/death file
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, RI has an integrated child health information system called KIDSNET, which links data from 10 programs including: Newborn Developmental Risk
Delivery Hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities, Maternal serum screening facilities
Other sources: Physician reports

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, All stillborn infants, All elective abortions, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, Chart reviews are conducted for infants born at the regional perinatal center and the 5 other maternity hospitals who were identified with an ICD-9-CM code 740-759 and 760.71, and other sentinel conditions
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM, ICD-10-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, Oracle

Data Analysis
Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration
System links: Link to other state registries/databases, KIDSNET, hospital discharge data
System integration: Integrated into KIDSNET for web-based provider reporting

Funding
Funding source: 5% General state funds, 10% MCH funds, 85% CDC grant

Other
Web site: www.health.ri.gov/programs/birthdefects
Surveillance reports on file: 2014 Rhode Island Birth Defects Data Book

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South Carolina

South Carolina Birth Defects Program (SCBDP)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Greenwood Genetics Center (GGC)
Program status: Currently collecting data
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 57,100
Statewide: Yes
Current legislation or rule: A281, R308, H4115
Legislation year enacted: 2004

Case Definition

Outcomes covered: Central nervous system defects, eye and ear defects, cardiovascular defects, orofacial defectcts, gastrointestinal defects, genitourinary defects, musculoskeletal defects, and chromosomal defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Up to two years of age
Residence: In-state births to state residents

Surveillance Methods

Case ascertainment: Active Case Finding
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, Elective termination certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Postmortem/pathology logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities
Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All prenatal diagnosed or suspected cases
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Access, SQL Server

Data Analysis

Data analysis software: SAS, Access, Arc-GIS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Time-space cluster analyses, Needs assessment, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link case finding data to final birth file
System integration: SCBDP data is integrated with SC Vital Records.

Funding

Funding source: 100% General state funds

Other

Web site:
http://www.scdhec.gov/Health/FamilyPlanning/DataStaticsonPregnancyBabyHealth/BirthDefects/

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South Dakota

Program status: No surveillance program

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Tennessee

Tennessee Birth Defects Registry (TBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals, Universities, Early Childhood Prevention Programs, Legislators
Program status: Currently collecting data
Start Year: 2000
Earliest year of available data: 1999
Organizational location: Department of Health (Vital Statistics, Office of Healthcare Statistics, Division of Policy Planning and Assessment)
Population covered annually: 85,000
Statewide: Yes
Current legislation or rule: TCA 68-5-506
Legislation year enacted: 2000

Case Definition

Outcomes covered: 45 major structural birth defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Prior to July 1st 2010: 500 grams or more, or in the absence of weight, 22 completed weeks of gestation or more; July 1st 2010 and later: 350 gra
Age: Up to one year after delivery
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: population-based
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Newborn metabolic screening program, Hospital Discharge Data System
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Other sources: Midwifery Facilities

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with selected procedure codes, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, ICD-9-CM code 760.71
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, SQL and SAS

Data Analysis

Data analysis software: SAS, Arc-GIS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Data/hospital audits
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Education/public awareness

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file

Funding

Funding source: 100% General state funds

Other

Web site: www.tn.gov/health
Surveillance reports on file: Tennessee Birth Defects Registry 2007-2012

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Texas

Texas Birth Defects Epidemiology and Surveillance Branch (TBDES)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Legislators, Researchers (NBDPN, NBDPS, ICBDSR)
Program status: Currently collecting data
Start Year: 1994
Earliest year of available data: 1996
Organizational location: Department of Health (Epidemiology/Environment)
Population covered annually: 387,110 in 2013
Statewide: Yes
Current legislation or rule: Health and Safety Code, Title 2, Subtitle D, Section1, Chapter 87
Legislation year enacted: 1993

Case Definition

Outcomes covered: All major structural birth defects and fetal alcohol syndrome.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: Up to one year after delivery and up to 6 years for FAS, special studies and childhood genetic disorders diagnosed after infancy.
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Active Case Finding, Population-based
Vital Records: Fetal death certificates for delivery year 2009 to present
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics, Genetics, stillbirths and radiology logs
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Postmortem/pathology logs, Surgery logs, Laboratory logs, Cardiac catheterization laboratories, Specialty outpatient clinics, genetics, stillbirths and radiology logs
Other sources: Midwifery Facilities, Licensed birthing centers

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Infants with low birth weight or low gestation (<34 weeks GA), All stillborn infants
Conditions warranting chart review beyond the newborn period: CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Oracle

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Clinical review, Timeliness, Re-casefinding, re-review of medical records
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Time-space cluster analyses, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration

System links: Link to other state registries/databases, Link to environmental databases, link registry to vital records for demographic data, special projects linking to other files (Texas Health Data for geocodes, Newborn Screening data).

Funding

Funding source: 48% General state funds, 52% MCH funds

Other

Web site: www.dshs.state.tx.us/birthdefects/
Surveillance reports on file: See website for publication and surveillance reports

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Utah

Utah Birth Defect Network (UBDN)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Education
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start Year: 1994
Earliest year of available data: 1994
Organizational location: Department of Health (CSHCN)
Population covered annually: 55,000
Statewide: Yes
Current legislation or rule: Birth Defect Rule (R398-5)
Legislation year enacted: 1999

Case Definition

Outcomes covered: Major structural malformations; newborn metabolic conditions; stillbirths
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (All gestational ages), Elective terminations (All gestational ages)
Age: 2 years based on mandatory reporting
Residence: Maternal residence in Utah at time of delivery

Surveillance Methods

Case ascertainment: Combination of active and passive case ascertainment; population-based
Vital Records: Birth certificates, Death certificates, Fetal birth certificate
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, CCHD screening program, Autism Registry
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Postmortem/pathology logs, Specialty outpatient clinics, Champions report live births delivered at their respective hospitals
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Cardiac catheterization laboratories, Specialty outpatient clinics
Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.), Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Midwifery Facilities, Physician reports, Lay midwives

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with a CDC/BPA code, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, All stillborn infants, All neonatal deaths, All infants in NICU or special care nursery, All prenatal diagnosed or suspected cases, All fetal death certificates, NICU reports, infant deaths are reviewed
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, Any infant with a codable defect
Coding: CDC coding system based on BPA

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Family history

Data Collection Methods and Storage

Data Collection: Printed abstract/report filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff using remote access from office (laptop, web-based, etc.)
Database collection and storage: Access

Data Analysis

Data analysis software: SAS, Access
Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review, Timeliness, Logical checks, duplicate check in tracking and surveillance module, case record form checked for completeness, timelin
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness, Prevention projects, Oral Facial Cleft Case-Control Study, UT Center for Birth Defects Research and Prevention, International Clearinghouse for Birth Defects, Local studies

System integration

System links: Link to other state registries/databases, Link to environmental databases, Link to Utah genealogic population database, Link to vital records
System integration: The database is linked with birth, death, and pulse oximetry screening data. Newborns having failed Pulse Oximetry Screening are integrated with UBDN.

Funding

Funding source: 100% MCH funds

Other

Web site: http://www.health.utah.gov/birthdefect
Surveillance reports on file: Http://ibis.health.utah.gov
Additional information on file: Scientific Collaboration Protocol

Comments: IBIS indicators for specific birth defects are online.

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Vermont

Birth Information Network (BIN)

Purpose: Surveillance, Referral to Services
Partner: Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Hospital Association
Program status: Currently collecting data
Start Year: 2006
Earliest year of available data: 2006
Organizational location: Department of Health (Division of Health Surveillance / Statistics)
Population covered annually: 6,200
Statewide: Yes
Current legislation or rule: Act 32 (TITLE 18 VSA §5087)
Legislation year enacted: 2003

Case Definition

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 week gestation and greater or a birth weight of more than 400 grams)
Age: Up to one year after delivery
Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Discharge summaries, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Discharge summaries, Specialty outpatient clinics
Third party payers: Medicaid databases, Multi-payer claims database
Other specialty facilities: Cytogenetic laboratories
Other sources: Physician reports, Autopsy reports

Case Ascertainment

Conditions warranting chart review in the newborn period: Any chart with selected procedure codes, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Any chart with an ICD-9-CM or ICD-10-CM code corresponding to a condition monitored by Vermont's registry.
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM, ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access

Data Analysis

Data analysis software: SPSS, Access, Excel
Quality assurance: Comparison/verification between multiple data sources, Data/hospital audits, Clinical review, Timeliness
Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Observed vs. expected analyses, Referral, Grant proposals, Education/public awareness

System integration

System links: Link to other state registries/databases, Link case finding data to final birth file, Link to environmental databases

Funding

Funding source: 5% General state funds, 95% CDC grant

Other

Web site: http://healthvermont.gov/tracking/health_birthdefects.aspx

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Virginia

Virginia Congenital Anomalies and Reporting Education System (VaCARES)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Local Health Departments, Hospitals
Program status: Currently collecting data
Start Year: 1985
Earliest year of available data: 2004
Organizational location: Department of Health (Office of Family Health Services, Division of Child and Family Health)
Population covered annually: 101,000
Statewide: Yes
Current legislation or rule: Code of Virginia, § 32.1-69.1
Legislation year enacted: 1985

Case Definition
Outcomes covered: Major and non-major birth defects
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Up to 2 years of age
Residence: Any diagnoses occurring in-state

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates
Other state based registries: Newborn hearing screening program, Newborn metabolic screening program
Delivery Hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries
Other specialty facilities: Genetic counseling/clinic genetic facilities

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)
Coding: ICD-9-CM, ICD-10 as of October 1, 2015

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Pregnancy/delivery complications
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.)
Database collection and storage: Oracle, Web-based reporting system is linked to electronic birth certificate and populates Oracle data tables

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks
Data use and analysis: Public health program evaluation, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Needs assessment, Referral, Grant proposals, Education/public awareness

System integration
System links: Link to other state registries/databases, Link case finding data to final birth file
System integration: VaCARES is part of the Virginia Vital Events Screening and Tracking System, which also houses electronic birth certificate reporting and the Virginia Early Hearing Detection and Intervention tracking.

Funding
Funding source: 97% MCH funds, 3% Genetic screening revenues
Web site: http://www.vdh.virginia.gov/livewell/programs/vacares/

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Washington

Washington State Birth Defects Surveillance System (BDSS)

Purpose: Surveillance
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Universities
Program status: Currently collecting data
Earliest year of available data: 1987
Organizational location: Department of Health (Office of Healthy Communities)
Population covered annually: 90,000
Statewide: Yes
Current legislation or rule: Notifiable Conditions: WAC 246-101
Legislation year enacted: 2000

Case Definition
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: We ascertain cases through 1 year of age for structural defects and to age 10 for FAS/FAE, Cerebral Palsy and Autism
Residence: Resident births; children born, diagnosed, or treated in-state

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates, Matched birth/death file, Fetal birth certificate
Other state based registries: Programs for children with special needs
Delivery Hospitals: Disease index or discharge index
Pediatric & tertiary care hospitals: Disease index or discharge index

Case Ascertainment
Coding: lCD-9-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Tests and procedures, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.)
Father: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Case-finding Log listing of all data elements required for each case are completed by Medical Records staff, sometimes in conjunction with hospital Information Systems staff. Several facilities submit print-outs from data query of internal system of discharge data. Minimal use of diskette or other forms of electronic data transfer. A web-based reporting system is currently in development.
Database collection and storage: Web-based SQL server

Data Analysis
Data analysis software: SAS, Stata
Quality assurance: Validity checks, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Baseline rates, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Education/public awareness

System integration
System links: Link case finding data to final birth file, CSHCN program participant file

Funding
Funding source: 70% General state funds, 30% MCH funds

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West Virginia

West Virginia Birth Defects Surveillance System

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services
Partner: Hospitals, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start Year: 1989
Earliest year of available data: 1989
Organizational location: Department of Health (Maternal and Child Health)
Population covered annually: 21,000
Statewide: Yes
Current legislation or rule: WV State Code 16-5-12a

Case Definition
Outcomes covered: ICD-9-CM codes 740-759, 760, 764, 765, 766 with transition to ICD-10
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (20 weeks gestation and greater)
Age: 0-6 years
Residence: In and out of state births to state residents

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital Records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, Elective termination certificates
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Infant and Maternal Mortality Review Panel
Delivery Hospitals: Discharge summaries
Pediatric & tertiary care hospitals: Discharge summaries
Other sources: Pediatric referrals of children not identified on birth certificate

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), Any birth certificate with a birth defect box checked, Infants with low birth weight or low gestation (<2500 grams or <37 weeks), All stillborn infants, All neonatal deaths, All elective abortions, All infants in NICU or special care nursery
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, Developmental delay, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematur
Coding: ICD-9-CM, transitioning to ICD-10

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Prenatal care, Prenatal diagnostic information, Family history
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Family history

Data Collection Methods and Storage
Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access

Data Analysis
Data analysis software: Access
Quality assurance: Comparison/verification between multiple data sources, Timeliness
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiologic studies (using only program data), Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

System integration
System links: Link to other state registries/databases, Link case finding data to final birth file

Funding
Funding source: 100% MCH funds

Other
Web site: http://wvdhhr.org/omcfh

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Wisconsin

Wisconsin Birth Defect Prevention and Surveillance System (WBDPSS)

Purpose: Surveillance, Research, Referral to Services
Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs
Program status: Currently collecting data
Start Year: 2004
Earliest year of available data: 2005
Organizational location: Department of Health (Maternal and Child Health, Department of Health Services, Division of Public Health)
Population covered annually: average 69,000
Statewide: Yes
Current legislation or rule: State statute 253.12 Birth defect prevention and surveillance system. Enacted December 2000. Department of Health Services rules, Chapter DHS 116 Wisconsin Birth Defect Prevention and Surveillance System. Enacted April 2003.
Legislation year enacted: 2000

Case Definition

Outcomes covered: A list of 87 specific birth defects are collected. The list may be viewed on our website at https://www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm. It is an appendix to the reporting form DPH 40054. The list was developed by the Scientific Committee of the Council on Birth Defect Prevention and Surveillance and is included as an appendix in the rules.
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater)
Age: Up to 2 years after delivery
Residence: All children born in and/or receiving services in the state

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation, Work with reporters who report batches from EMRs to assure reporting quality
Vital Records: Matched birth/death file, compare registry reports to vital records periodically for selected birth defects

Case Ascertainment

Coding: ICD-9-CM, State assigned codes assigned to all conditions collected. Reporters combine ICD-9-CM or ICD-10 with text searches to derive defects that share an ICD code.

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data Collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Can submit one report on the website or upload multiple reports. A paper form is also available that is entered by state birth defects staff.
Database collection and storage: Oracle

Data Analysis

Data analysis software: SAS
Quality assurance: Validity checks, Comparison/verification between multiple data sources
Data use and analysis: Routine statistical monitoring, Rates by demographic and other variables, Time trends, Observed vs. expected analyses, Referral, Grant proposals, Prevention projects

Funding

Funding source: 100% birth certificate fees
Web site: https://www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm
Surveillance reports on file: Posted on the website

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Wyoming

Program status: Interested in developing a surveillance program

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Department of Defense

United States Department of Defense (DoD) Birth and Infant Health Registry

Purpose: Surveillance, Research
Partner: Hospitals, Universities, Other DoD Programs
Program status: Currently collecting data
Start Year: 1998
Earliest year of available data: 1998
Organizational location: Deployment Health Research Department, Naval Health Research Center
Population covered annually: Approximately 100,000 per year
Statewide: No, National/Worldwide; includes all DoD beneficiaries
Current legislation or rule: Assistant Secretary of Defense, Health Affairs Policy Memorandum
Legislation year enacted: 1998

Case Definition
Outcomes covered: Outcomes include those birth defects listed in the case definition of the National Birth Defects Prevention Network. For a birth defect to be represented, the diagnosis must appear at least once in an inpatient record, or at least twice on two separate dates for outpatient encounters. Same sex multiples are excluded from analysis.
Pregnancy outcome: Livebirths (All gestational ages and birth weights)
Age: Birth up to one year after delivery
Residence: Worldwide; any birth to a US military beneficiary

Surveillance Methods
Case ascertainment: Active Case Finding, Passive case-finding with case confirmation, Passive case-finding without case confirmation, Electronic diagnostic codes from all inpatient and outpatient healthcare encounters of US military beneficiaries at both civilian and militar
Delivery Hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, All inpatient and outpatient encounters at both civilian and military care facilities are captured in standardized DoD data
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics, All inpatient and outpatient encounters at both civilian and military care facilities are captured in standardized DoD data
Third party payers: All inpatient and outpatient encounters at both civilian and military care facilities are captured in standardized DoD data
Other sources: Validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from military facilities

Case Ascertainment
Conditions warranting chart review in the newborn period: Any chart with an ICD-9-CM code 740-759, Any chart with a selected list of ICD-9-CM codes outside 740-759, Validation of standardized electronic data performed by active case ascertainment and chart review of a random sample of births from military healthcare facilities
Conditions warranting chart review beyond the newborn period: Any infant with a codable defect
Coding: ICD-9-CM

Data Collected
Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information
Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications
Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Illnesses/conditions

Data Collection Methods and Storage
Data Collection: Electronic file/report submitted by other agencies (hospitals, etc.)
Database collection and storage: Access, SAS

Data Analysis
Data analysis software: SAS
Quality assurance: Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review
Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiologic studies (using only program data), Identification of potential cases for other epidemiologic studies, Grant proposals, Prevention projects, Monitor birth defect outcomes following specific parental or gestational exposures of concern

System integration
System links: DoD databases
System integration: DoD databases

Funding
Funding source: 100% Other federal funding (non-CDC grants)

Other
Web site: http://www.med.navy.mil/sites/nhrc/Pages/Research-and-Development-Focus-Areas.aspx?Category=MILITARY-RANDDFOCUS
Surveillance reports on file: DoD/Health Affairs policy memorandum; annual reports

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